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UNIVERSITY OF ALBERTA

WORK REENTRY AFTER BRAIN INJURY

BY

ELLEN BOELCKE

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of MASTER OF EDUCATION

in

ADULT AND HIGHER EDUCATION

DEPARTMENT OF ADULT, CAREER AND TECHNOLOGY EDUCATION

Edmonton, Alberta

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled WORK REENTRY AFTER BRAIN INJURY submitted by ELLEN BOELCKE in partial fulfillment of the requirements for the degree of MASTER OF EDUCATION, in ADULT AND HIGHER EDUCATION.

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September 26, 1994

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Abstract

This research study adopted a qualitative research paradigm utilizing in-depth interviews to explore the return to work needs of eight adults (age 16 and over) who had experienced a moderate or severe brain injury. Thematic analysis of the resultant transcripts identified factors that the participants themselves perceived as being important in facilitating return to work. In general, participants were unanimous in their endorsement of the utility of vocational rehabilitation programs. They identified significant changes in emotional, cognitive and social functioning as a result of their brain injuries, which, in turn, impacted on their return to work. The study revealed a number of barriers to returning to work including the present depressed economy and lack of employer knowledge about brain injuries. Participants felt that support from family, peers, co-workers and rehabilitation staff assisted in returning to work. Participants also maintained that rehabilitation programs needed to focus greater attention on participant motivation and the timing of return to work. A need to individualize programs, allow for comprehensive follow-along in supported employment and encourage assumption of personal control and responsibility was identified. Work experiences were believed to be very important, but the need to match personal interests with vocational experiences was stressed. A need for public education was also identified. The results of the study emphasize the importance of comprehensive vocational programs, increased accessibility to such programs and the need to explore ways to provide incentives to encourage employment of those with brain injuries. Finally, the study concludes with suggestions for future research.

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Chapter 1

Overview of the Problem

Introduction

In the latter half of this century, trauma has been called the plague of modern society (Blocker, 1986). In the United States, of the 1.9 million people injured each year, 400,000 - 500,000 are hospitalized, many of these with severe traumatic injury to the brain (Blocker, 1986). In Canada, it is estimated 200 cases per 100,000 population require hospitalization each year as a result of traumatic brain injury (Parkinson, Stephenson, & Phillips, 1985). The incidence rate for strokes, another major cause of brain injury not considered in the traumatic brain injury statistics, is estimated at 250 per 100,000 population (Alberta Health, 1991).

Most commonly, brain injury occurs as a result of car, motorcycle or sports accidents or, to a lesser degree, the result of falls, encephalitis, lack of oxygen to the brain, or cerebral hemorrhage (Richardson, 1990). Typically, strokes are included in the latter two categories. Recent advances in medicine and technology have saved the lives of brain trauma victims and, to an extent, have contained the destruction of brain tissue. Thus, many more people are surviving brain injuries that, in the past, would have been fatal. These individuals, however, often suffer severe and pervasive brain damage with chronic sequelae.

Recovery from brain injury is varied. Recovery can, at one point of a continuum, lead to total independence, while at the other extreme lies complete dependence. Many factors determine the degree or extent of recovery from brain injury. Brain injury can result in pervasive disabilities including physical, cognitive, psychosocial and emotional deficits, which create substantial, and often indefinite, long-term needs and responsibilities (DeJong & Batavia, 1989; DeJong, Batavia, & Williams, 1990). The

extent of medical advances in dealing with brain injuries has been impressive. Unfortunately, rehabilitation for brain injury victims has not kept pace with advances in medical technology. Research suggests that brain injury is a complex and devastating problem, not only for the persons with brain injury, but also for family, service providers and society in general (DeJong et al., 1990).

Problem Statement and Research Questions

Advances in medicine and technology, unfortunately, cannot repair the brain damage that can occur as a consequence of brain trauma. These advances can also not "inhibit all the deleterious reactions in the chain of secondary physiological events set in motion by the trauma" (Lezak, 1989, p. ix). Many individuals whose lives are saved as a result of modern medicine suffer significant and permanent brain damage. "Most of these people are sufficiently compromised to require specialized vocational services if they are to return to the workforce" (Wehman & Goodall, 1990, p.1). Studies show that the ability to attain and maintain employment rests on many cognitive, psychosocial, physical and behavioral factors.

A common belief is that individuals with brain injury cannot be helped very much by rehabilitation and that "return to the community is mostly a matter of spontaneous recovery" (Diller, 1990, p. xiii). Many people with brain injury, immediately following an initial recovery period, and often in response to environmental pressures, embark upon ill-advised pursuits with devastating results (Silver & Kay, 1989). People with less obvious symptoms are more likely to return to the work force too early, only to be faced with employers and co-workers who misinterpret some of their behaviors, and are easily frustrated by the individual's unusual behavior.

O'Hara (1988) concluded that an inability to understand behaviors and symptoms may lead to isolation of the individual on the job, rather than developing much needed work site supports, which are necessary to understand and resolve the issues at hand.

Others with brain injury become clients of service systems designed for persons with developmental disability, psychiatric disorders, or physical impairments. In general, "these programs are unable to provide appropriate and comprehensive rehabilitation services to persons with head injury" (Veldheer, 1990, p. 24). Veldheer (1990) further states that, due to limited programs and financial support, many people with brain injury remain in a condition of dependency. Usually those with brain injury are dependent on family members.

Evidence is incontrovertible that persons with brain injury have poor return to work employment rates (Brooks, McKinlay, Symington, Beattie, & Campsie, 1987; McMordie, Barker, & Paolo, 1990; Oddy, Coughlan, Tyerman, & Jenkins, 1985; Prigatano, Klonoff, & Bailey, 1987; Wehman & Goodall, 1990). For example, one study investigating the vocational outcome within 7 years of severe brain injury showed that work return rates fell from 86% pre-injury to 29% post-injury (Brooks et al., 1987). McMordie et al. (1990) found only 19% of 177 patients with brain injury were competitively employed at a mean of 6.7 years post-injury.

Further, when viewing the employment statistics for persons with brain injury, one must be aware that it is much more complex than simply viewing the percentage of people who regain employment. Many of those who return to work may hold less demanding or more menial positions, may be placed in sheltered employment, may hold volunteer work, or may work for "benevolent employers in positions having no specific duties or accountability" (Sale, West, Sherron, & Wehman, 1991, p.2).

Vocational rehabilitation research of those with brain injury is still quite new. Much of the research focuses on the design and outcome of programs originally developed specifically for other disability groups. Specialized employment programs for persons with brain injury are largely modifications of programs designed for persons with developmental disabilities (Veldheer, 1990). The short-term results of these modified

programs are only slightly encouraging. Long-term study results showing rates of acquisition and maintenance of employment for the brain injury population are just starting to emerge in the literature. The vocational rehabilitation program method that has shown much promise is that of supported employment with on-the-job training (Wehman & Kreutzer, 1990). Supported employment means that the staff person or "job coach" provides work-site specialized assistance to aid the person with brain injury to attain, learn and maintain a job. The duties of a job coach may include arranging the placement, providing on-site training, support and advocacy, and follow-up for job maintenance. It is assumed that, without this service, the participant would be unlikely to obtain or hold employment (Wehman, Kreutzer, Wood, Morton, & Sherron,1988).

Other studies provide professional, community worker and family input on what the person with brain injury needs in order to be gainfully employed (Ben-Yishay, Silver, Piasetsky, & Rattok, 1987; Haffey & Abrams, 1991; Wehman, Kreutzer, Wood, Morton, & Sherron, 1988). None of the studies reviewed asked the opinions of the clients--their perception of what is of benefit, and what is necessary to enable them to return to employment.

This study focused on the work reentry experiences of adults (age 16 and over) who are recovering from a brain injury. A key objective of this research was to identify commonalities, factors and core issues in relation to reemployment from the perspective of individuals with brain injuries. Therefore, this study was intended to identify the factors that clients themselves perceive as being of primary importance in vocational rehabilitation programs that facilitate their return to work. The research questions addressed in this study were:

What factors affect return to employment from the perspective of individuals who have sustained a brain injury?

What can be done to facilitate and improve the rehabilitation process from the perspective of individuals who have sustained a brain injury?

Definition of Terms

The following definitions will be used in this study:

Brain Injury -- "a major interruption of brain function occurring after birth, in which the functional and behavioral effects can be arrested or reversed. The definition describes a client population with similar treatment, rehabilitation, management and care needs regardless of the cause of the injury" (Alberta Health, 1991, p. 1).

Competitive employment -- a job within the community paying at least the provincial minimum wage without subsidy, where the worker is considered to be a regular employee.

Stroke -- "a sudden appearance of neurological symptoms as a result of severe interruption of blood flow" which can result from a wide variety of different vascular diseases (Kolb & Whishaw,1985, p. 117).

Vocational rehabilitation program -- any program designed to aid persons to return to personal maximum employment potential.

Work reentry -- to enter the work force again after a period of absence.

Organization of Thesis

This thesis is organized in five chapters. The first chapter provides an introduction and overview to the study. Chapter Two provides a review of the literature related to brain injury epidemiology, functional recovery and long-term impairments, and work reentry for persons recovering from brain injury. In Chapter Three the research methodology is outlined and the sample is described. Chapter Three also introduces the Edmonton, Alberta based vocational rehabilitation program from which the sample was drawn. The results are presented in Chapter Four and discussed in Chapter Five.

Chapter 2

Review of the Literature

> The brain is the source of everything that we are. It is the source of everything that makes us human, humane, and unique. It is the source of our ability to speak, to write, to think, to create, to love, to laugh, to despair, and to hate (Andreasen, 1984, p. 93).

This chapter provides an introductory review of the relevant literature on brain injury and employment. Epidemiology of brain injury, functional recovery from brain injury and long-term impairments associated with brain injury, competitive employment for persons with brain injury, employment studies, work reentry factors, and vocational rehabilitation models are discussed.

Brain Injury: Epidemiology, Functional Recovery and Long-Term Impairments

Brain injury is defined as a major interruption of brain function, acquired after birth, in which the functional and behavioral effects can be arrested or reversed. The definition describes a group of people with similar treatment, rehabilitation, management and care needs regardless of etiology (Alberta Health, 1991). As noted, brain injury most commonly occurs as a result of motor vehicle accidents or, to a lesser degree, the result of falls, encephalitis or vascular disease. The types of brain injury relevant to this thesis are discussed in this section under the broad categories of vascular disease or stroke, and traumatic brain injury.

In the past, people who sustained a moderate or severe brain injury often died. Within the last 20-30 years, medical techniques have improved to the point that individuals may survive after suffering an injury, but frequently they, and their families, have to adjust to a totally different kind of life (NABIS, 1991). These individuals are often left with permanent mental and physical impairments and may, depending on the severity of their injury, never return to their former lifestyle. Brain injury has only

recently been recognized as an area deserving of and requiring specialized attention. There has been an upsurge of professional attention over the past 10 years. In this time, three journals relating to this topic have begun publication. These are: Cognitive Rehabilitation started in 1982, Journal of Head Trauma Rehabilitation started in 1985 and Brain Injury from 1987.

Statistics show the tremendous ramifications, personal and societal, of brain injury, and concomitantly, highlight the need for programs and research to address the needs of this special population (DeJong et al., 1990). For example, the National Head Injury Foundation of the United States maintains that brain injury is the major cause of death in North America for people under the age of 34. In Canada, it is estimated that 200 cases per 100,000 population require hospitalization for traumatic brain injuries annually (Parkinson et al., 1985). Using this incidence figure, Alberta experiences approximately 4860 new cases per year requiring hospitalization. In addition to these figures, it is estimated that 360 Albertans die of a traumatic brain injury before reaching hospital (Alberta Health, 1991). Further, the incidence rate for strokes is estimated at 250 per 100,000 population, equating to 6070 persons per year in Alberta requiring hospitalization for this type of brain injury (Alberta Health, 1991). Statistics are not available for other causes of brain injury such as surgical procedures, anoxia, chemicals and infections (Alberta Health, 1991). Total and accurate incidence figures are therefore greater than estimated. Many of these brain injuries can be rated as mild and often do not require intense intervention. However, individuals who survive a moderate or serious brain injury are often permanently disabled to some degree and require special long-term programs to address their specific needs (DeJong et al.,1990, DeJong & Batavia, 1989).

Vascular Diseases (Stroke). Vascular diseases are a serious neurologic problem that remains one of the common causes of death in North America and most European countries and is a leading cause of chronic disability (Hachinski & Norris 1985; Kelley,

1994). A common term used in discussing vascular disorders is stroke. However, confusion exists over terminology related to strokes and there are often overlaps and vague categories that confuse etiology, anatomy and symptomatology (Hachinski & Norris, 1985). The term "cerebrovascular" appropriately describes most strokes, although cerebral arteries also receive cardiac emboli (a clot or other plug which obstructs circulation), and thus the term cardiovascular may apply to certain strokes. Kolb and Whishaw (1985, p. 117) maintain that stroke refers to "a sudden appearance of neurological symptoms as a result of severe interruption of blood flow" and note that strokes can result from a wide variety of different vascular diseases. Strokes often produce an "infarct" or area of dead or dying tissue resulting from obstruction of the blood vessels and serious, even total reduction, of oxygen and glucose which are essential to cell survival. Strokes result from identifiable and predictable causes and occur with the greatest frequency in the distribution of the middle cerebral artery, with infarctions typically occurring in one cerebral hemisphere (Meier, Straumann, & Thompson, 1987).

The most common vascular disorders that affect the brain are: 1) decrease in blood flow as a result of thrombosis, embolisms or cerebral arteriosclerosis; 2) cerebral hemorrhage or massive bleeding into the substance of the brain and, 3) aneurysms or vascular dilations (outpouchings described as berry or saccular) resulting from localized defects in the elasticity of the blood vessels (Kelley, 1994). Over the past three decades stroke has changed from being diagnosable, but untreatable, to a treatable condition, although prognosis for recovery from strokes may depend on vascular location, nature, severity and number of lesions and neurophysiological mechanisms of recovery (Ryerson, 1985).

Functional Recovery from Vascular Disease (Stroke). There is a wide variation in recovery, although sensorimotor functions show the earliest recovery and plateau, whereas higher level cortical functions may show recovery up to three years post-episode

(Meier et al., 1987). However, the severity of the stroke is one of the most important factors in recovery and this is usually reflected in impaired consciousness, with coma a poor prognostic indicator. Mortality rates in stroke are around 20% in the first month. Aneurysms are usually weak and prone to rupture causing cerebral hemorrhages which are typically more serious than infarction (Kelley, 1994). Strokes can result in specific neurological deficits including hemiplegia, sensory dysfunction, aphasia, dysarthria, visual field deficits and mental and intellectual impairments. Psychosocial adjustments may be more detrimental to long-term stroke survivors than functional disability (Ryerson, 1985) and the number of long-term stroke survivors who return to work can be very low (Fugl-Meyer, 1980).

Traumatic Brain Injury. A number of factors distinguish traumatic brain injury from other cerebral disorders, including sudden onset, age group of patients, potential extensiveness and patterns of brain damage, and coma (Smith, 1985). Brain injury can result from either open or closed head injury (Richardson, 1990). In open head trauma, there is injury to the scalp and the skull is actually broken, either as a result of penetration or from the effects of the force used. Closed head injury is often caused by a blunt object hitting the skull, causing, in some cases, the skull to pull away from the brain, or in other cases, causing the skull to be crushed inward without breaking. The skull remains intact without obvious external damage. This is called injury by compression. In both types of trauma a brain injury may occur. The effects may be chronic or acute, but will depend on the specific area, location of injury, and most importantly on the extent of not only primary damage, but also secondary damage to brain tissue.

In traumatic brain injuries, acceleration, deceleration, and rotational forces can act on the head at the time of injury or impact (Smith, 1985). This may cause temporary deformation of the skull. The actual brain damage can be caused by tissue compression, tension, shearing or a combination of these mechanisms. Injuries to the brain can be coup

(at the site of the impact) or contrecoup (distant from the part of the brain injured by impact). In acceleration injuries the contents of the head can be damaged by impact with the bony irregularities at the base of the cranial vault. Coup and contrecoup injuries can also result when there is rapid deceleration of the skull. Shearing forces are the major cause of contrecoup injuries to the brain as a result of rotation and movement of the brain within the cranial vault and can be very destructive.

There are two categories of traumatic brain injury: primary and secondary damage. Primary damage, which occurs instantaneously (Pang, 1989), includes skull fractures, contusions of the gray matter and diffuse white matter lesions (Smith, 1985). Secondary damage occurs as an epiphenomena causally related to primary brain damage (Pang, 1989), and includes swelling, intercranial hematoma, cerebral hypoxia and ischemia (Smith, 1985). Therefore, damage is caused, not only to the primary trauma site, but also may be diffuse and more wide-ranging or globalized because of other factors such as shearing and hemorrhaging that can further damage the brain. These combine to produce a great deal of variability in physical, cognitive and psychosocial impairments and recovery (Sohlberg & Mateer, 1989). Modern management of brain injury affects physical outcome through minimization of secondary brain injuries (Pang, 1989), although much of the morbidity associated with traumatic brain injuries still results from secondary insult or damage.

Functional Recovery from Traumatic Brain Injury. Commonly, complete loss of consciousness occurs after brain trauma. Jennett (1990) reviewed studies that assessed the recovery of patients with brain injury and concluded that the longer the period of unconsciousness resulting from an injury, the more likely it is that permanent brain damage has occurred. Controversy exists over the relationship between retrograde amnesia (loss of ability to recall events that have occurred during the period immediately preceding injury) and the severity of injury. Post-traumatic amnesia (the time lapse

between accident and the point at which functions related to memory are restored) is, however, a reliable indicator of severity of injury (Cartlidge & Shaw, 1981; Levin, Benton & Grossman, 1982; Sohlberg & Mateer, 1989,).

Specific factors relating to recovery from brain injury include the mechanism of injury, specific etiologic factors, patient susceptibility to injury, severity of brain injury, neuropathology, impaired consciousness, secondary brain injury and systemic injuries, time since symptom onset, variations in cerebral organization or dominance that may favour/disfavor lateralization of higher cortical functions, premorbid environmental or lifestyle factors such as education, nutrition, vocational level, and physical and psychological health (Levin, Hamilton, & Grossman, 1990; Meier et al., 1987). Current knowledge of each of these variables and how they apply to any one person is uncertain and there is enormous variability in the prospects of recovery.

In addition, perception of recovery following head injury is multifaceted and may depend on measures of recovery used, time from injury and who is making the judgement (Levin, et al., 1982). Recovery from brain injury depends, not only on the type, location, and extent of brain damage, but also on "the attitude of the person and the attitude and support of physicians, therapists and family" (Kolb & Whishaw, 1985, p. 634). In relation to attitudes, Finger and Stein (1982) stated that many people have an expectation that recovery will not occur and they consequently do not encourage rehabilitation, while others may be overly optimistic. Recovery is seldom quick, but usually involves slow change. Precisely what changes occur will depend on the type of brain damage (Levin et al., 1990). "The more extensive the damage appears to be, the poorer are the prospects for recovery" (Kolb & Whishaw, 1985, p. 660).

Deficits resulting from stroke and head injury may typically be different (Levin, Benton, & Grossman 1990; Meier et al., 1987; Newcombe, 1982). Strokes may produce well-defined lesions and specific lateralized deficits, whereas traumatic brain injuries

may result in diffuse impairments and non-lateralized cognitive dysfunction. Further research is clearly needed to address the need for differential treatment strategies, but equally apparent in both types of injury is the need for comprehensive rehabilitation programs, particularly with respect to vocation and return to work.

Long-Term Impairments Associated with Brain Injury. Stoffles (1988) provides a brief summary list of the major impairments that may be associated with brain injury. For physical impairments this report lists: speech, vision, hearing, headaches, lack of coordination, spasticity of muscles, paralysis of one or both sides, and seizure disorders. Cognitive deficits may include: memory loss, poor concentration, slow thinking, short attention span, lack of awareness of deficits, and impaired communication. In addition, reading and writing skills, and planning and sequencing may deteriorate. Judgement may also become impaired. Further, many persons with brain injury may also experience impairments in the areas relating to psychosocial functioning. These include: fatigue, mood swings, denial, self-centeredness, agitation, anxiety, depression, poor self-monitoring, emotional lack of control, sexual dysfunction, restlessness, lack of motivation, inability to cope, excessive laughing or crying (lability), and difficulties relating to others. Typically, cognitive, emotional and behavioral sequelae greatly exceed the physical (e.g., motor deficits) and may be more disabling (Jennett, Snoek, Bond, & Brooks, 1981; Paniak, Shore, Rourke, Finlayson, & Moustacalis, 1992), particularly with respect to the cause of difficulties in work reentry (Ben-Yishay et al., 1987).

The extensive list of impairments associated with brain injury emphasizes the diverse nature of the possible symptoms of a brain injury. "With or without physical problems, these symptoms often lead to chronic unemployment" (Gobble, Henry, Pfahl, & Smith, 1987, p.221). Vocational rehabilitation programs that strive to provide comprehensive services to clients with brain injury must incorporate treatment of those

impairments identified. These functions may affect the focus of, as well as obstacles to, successful attainment and maintenance of employment.

Employment for Persons with Brain Injury

Employment for persons recovering from a brain injury is important for a number of reasons. In our society, it is important to feel needed and to know that someone else can depend on you (Jacobs, Blatnick, & Sandhorst, 1990). Beside the financial considerations, there is also the personal demoralization that can occur when people question their contribution and worth to society. The sense of helplessness and lack of self-worth are readily apparent when individuals are seen as social burdens rather than social contributors. This is true for all in our society, including those individuals who have sustained a brain injury. Once individuals have returned to the community, they no longer want to be known as just survivors of a brain injury, but as people who have much to contribute to society.

The importance of this issue is even more apparent when viewed in light of the age of most injury accidents. The majority of brain injuries happen to young adults who are at the beginning stages of establishing themselves in society through work and education (DeJong et al., 1990). These young people are then left without a legitimate place in society, no way to re-establish a position, and are dependent on their families and society. As well, they face a long life of uncertainty, because, after having survived the brain injury, current literature suggests they have a normal life expectancy (Fraser, Dikmen, McLean, Miller, & Temkin, 1988; Levin et al., 1982). The needs for care and assistance and the cost of meeting such needs are enormous and increasing at an alarming rate as the total number of persons with brain injuries increases each year (DeJong & Batavia, 1990).

Employment Studies

In recent years, various studies regarding vocational potential and outcomes of those sustaining a brain injury have been conducted and are discussed in this section. The first studies were conducted with persons who had suffered brain injury, but did not receive specialized vocational rehabilitation, while the latter studies focus on results obtained after comprehensive vocational training.

Brooks et al. (1987) followed 98 patients to determine employment status within seven years after brain injury. After determining a pre-injury unemployment rate of 14%, their study indicated that 71% of the group studied were unemployed after injury. Factors identified as contributing to unemployment were cognitive status (attention, memory and communication deficits), personality problems and behavioral disorders. Haffey and Lewis (1989) reported a natural return to work rate of between 23-30% after severe brain injury. The researchers also reported that, of those that are able to return to work, up to 40% experience difficulties that result in marked change of duties or termination of employment.

While research outcomes differ demographically and geographically, common findings for persons with brain injury with little or no vocational rehabilitation point to post-injury high unemployment rates, reduced vocational status and decreased job retention abilities in competitive employment (Sale et al., 1991). These studies highlight the need to develop better vocational rehabilitation programs to reduce factors associated with unemployment and underemployment.

Overall, studies show the following results. The severity and type of injury are determinants, although not the only factors, which predict post-injury employment status; less that 50% of persons with moderate to severe injuries are typically employed post-injury; and few persons with brain injuries achieve and maintain employment at levels comparable to those held pre-injury (Kay,1989; McMordie et al., 1990; Wehman,

Kreutzer, Wood, Morton, & Sherron, 1988). Many studies suggest the major factors associated with finding and maintaining employment include cognitive, behavioral, social and physical status, as well as the degree of support, services and resources available to the person with brain injury (Goll & Hawley, 1989; Johnson, 1987; Malkmus, 1989).

The results of the most comprehensive and detailed studies of specialized vocational rehabilitation programs specifically for persons with brain injury are showing increased job attainment and maintenance compared to no vocational rehabilitation. Ben-Yishay et al.'s (1987) preliminary results appear promising. At the completion of the occupational trials, 63% (of 94 clients) were found to have attained the ability to engage in competitive employment, while 30% were in productive, but noncompetitive work placements. In a follow-up study, results showed that, after a 36 month period, 50% of the persons in competitive employment remained at the same work level, and 22% remained in noncompetitive work positions (Ben-Yishay et al., 1987). Prigatano's (1988) study reported 65% of the clients completing a vocational rehabilitation program were successfully employed at discharge, and 50% maintained employment for a one year duration. Haffey and Abrams (1991) reported preliminary return to work rates of 68%, and introductory retention results 48% of the original sample.

The studies just discussed have to be interpreted with caution, however. The major critique of these studies is their sample selection. Prigatano (1988) and Haffey and Abrams' (1991) studies used consecutively admitted patients--admission based on the criteria that they had "adequate potential" or "some employment potential" to return to some level of employment. The criteria are not defined. Ben-Yishay et al.'s (1987) criteria for program admission were quite strict, resulting in a limited sample of individuals with high potential. Further, final statistical results did not include in the sample patients who were expelled for noncompliance or who failed to complete any phase of the program. This places some doubt on the generalizability of their findings.

Disparities in research findings are in all likelihood attributable to the great variability in the range of severity of brain injury among the groups, difficulties establishing criteria for severity, and thus difficulty equating severity across different studies (Fraser et al., 1988). Lack of objective comprehensive standardized neuropsychological assessments may preclude assessing the effect cognitive impairments may have on return to work (Fraser et al., 1988). Preexisting conditions may be ignored and the length of interventions and follow-up may vary considerably. Moreover, there is an absence of uniform criteria for defining what constitutes resumption of work, a lack of adequate and consistent verification of work performance and status, varying entrance and outcome criteria, and an absence of reliable follow-up over longer periods of time (Ben-Yishay et al., 1987; Fraser et al., 1988; Humphrey & Oddy, 1980).

Work Reentry Factors

The literature highlights a number of factors that affect work reentry for persons recovering from brain injury. These key issues are believed to impinge upon the return to work of persons with brain injury. Various authors argue for their inclusion in vocational programs to maximize success for work reentry.

First, a person's pre-injury vocational competence and motivation must be assessed. This aids in evaluating what type of worker the individual was in the past, and the area in which to focus job development efforts, "at least initially" in order to aid in future job placements (Wehman & Goodall, 1990, p. 5). Second, one must investigate the person's post-injury vocational competence and motivation (Wehman & Goodall, 1990). This includes discovering what degree of commitment the individual has to be employed again, and also which job(s) are of interest and potential attainment of skill level in job success.

Next, one must determine the physical and medical status of the individual. Many individuals with a brain injury experience physical, and medical problems that interfere

with gaining and maintaining employment (Brooks et al., 1987). Fourth, diagnosing psychiatric and maladaptive behavior will aid in the development of the reentry program. Major barriers in achieving secure employment for persons with brain injuries are emotional and interpersonal difficulties (Hendryx, 1989; Wehman & Goodall, 1990; Wehman et al., 1988).

Research studies have shown a relationship between alcohol use and brain injuries (Goodall, 1989). For this reason, one must determine if or how much of a factor, substance use or abuse is, for the individual. Beyond negative physical and emotional consequences, substance abuse can adversely affect an individual's employment opportunities (Eames, 1988). Sixth, the individual's family or marital status must be assessed. The injury itself, and all events following, will have effects on, and be affected by, family relationships. Research studies have shown that the family of an individual with a disability is important in the successful implementation of community-based employment (Kreutzer & Wehman, 1990; Moon, Goodall, Barcus, & Brooke, 1986). "In light of the changes that occur within the family and the family's importance in rehabilitation efforts, family members must be included as a vital part of the supported employment team" (Wehman & Goodall, 1990, p. 8).

Seventh, the individual's personal pre- and post-injury vocational goals and expectations are of vital importance. Given that people work most effectively in jobs that they enjoy, a quality vocational program must concentrate on the individual's interests and preferences (Fraser et al., 1988). Most adults, prior to sustaining a brain injury, have either worked, or had aspirations to work, in a particular career. It must be recognized that, for most persons with severe injuries, a return to prior levels of functioning may not be feasible (Oddy & Humphrey, 1980; Thomsen, 1984; Veldheer, 1990). However, when concerned with the quality of life and motivation of the individual, their aspirations must be taken into consideration. Wehman and Goodall (1990) stated that this assumption

may even be more relevant for persons with a brain injury for they have often lost control over much of their life and, therefore, feel a need to gain control over at least some aspects of their lives. Their goals and expectations must be compared to their existing and potential skills to test for reality. "Many individuals hold unrealistic vocational expectations because the brain injury itself may cause diminished self-sight and lowered ability to solve problems and perceive situations correctly" (Wehman & Goodall, 1990, p. 9).

Finally, the program must match the characteristics of the individual with a specific job. A complete analysis of job requirements must be completed and matched appropriately with the client's present skills and learning potential. Along with the actual duties to be performed on the job and the issues discussed above, it is important to consider other potential barriers such as transportation and physical limitations (Wehman & Goodall, 1990).

The tremendous importance and potential for the role of education pertaining to employment issues, for individuals, employers and society cannot be overlooked. The effects of brain injury are often not readily visible and brain injury has aptly been given the name of "the silent epidemic." Persons who sustain a brain injury may not receive the same consideration as other individuals who have a more visible disability. Individuals with brain injury are often exposed to a lack of understanding and/or prejudice in their social and vocational environment. These factors suggest a number of further considerations that a successful vocational reentry program must address including the inclusion of family, employer, co-worker and societal education in vocational rehabilitation programs.

In summary, the above factors address pre-injury and post-injury competence and motivation, physical, medical, psychological, sociological and support status, psychosocial behavior, vocational goals, job match and public education. If these issues

are not properly addressed, job attainment and long-term employment may be very difficult, if not impossible, for persons recovering from brain injury. These factors, according to prominent researchers in this field, must all be incorporated into a community-based employment program to achieve the best quality program possible. Each impinges, to varying degrees, upon successful return to work for persons with brain injury.

Vocational Rehabilitation Models

In the past, brain injury rehabilitation occurred only within a hospital setting. Many of the medical and physical problems were addressed, but then the individual was discharged with limited or no further services or follow-up (Hayden & Hart, 1986). This reflected the basic philosophy of spontaneous recovery endorsed at that time. It is now known that there is a great deal of potential for learning and rehabilitation of persons with brain injury. Therefore, rehabilitation must include the establishment of long-term goals extending well into the reentry of the individual with brain injury into the community. This includes various aspects of the person's life, such as developing and maintaining intact support systems, healthy leisure opportunities and, in many cases, the facilitation of participation in meaningful employment. Employment takes on a special significance when one considers the young age and work potential of the majority of the persons recovering from brain injury (Goll & Hawley, 1989).

The rehabilitation process is costly. Programs and goals must remain realistic and achievable. This is a concern, not only to the individual and his or her family, but also to Canadian society which funds a universal medical system. Proper rehabilitation for persons with brain injury enhances and accelerates recovery and improvement, while minimizing deficits (Abrams, Barker, Haffey, & Nelson, 1993). Proper treatment lessens the residual deficits in brain injury and substantially reduces costs to taxpayers in the long run. Most importantly, "good rehabilitation and medical care improves the quality of life

and reduces the financial exposure on a long term basis" (Bistany, 1987, p. 99). Successful rehabilitation is thus a cost effective measure (Cope & O'Lear, 1993; Abrams et al., 1993).

In response to the poor post-injury employment statistics for brain injury, many models of vocational rehabilitation have been proposed and implemented. Initial models used to aid persons in attaining employment were linear, implemented after the clients were discharged from hospital settings. Most commonly, they comprised of intake, assessment, planning, training and placement phases. In these traditional models, a progressive stage system was implemented; thus, only with the completion of the previous stage did the client progress to the next. This process brought the client into contact with a series of professionals and a succession of activities and agencies. Examples of linear models are discussed in Goll and Hawley (1989), Lyons and Morse (1988), and Stein (1984).

In these linear approaches, vocational services begin only after all physical rehabilitation has taken place (Fawber & Wachter, 1987). Medical rehabilitation and vocational rehabilitation practitioners view the client at different stages of the rehabilitation and in varying settings and, thereby, were prone to view clients' functional capacities and abilities in different ways. Further, difficulty was experienced in establishing and maintaining linkages between acute services and community rehabilitation which were necessary to provide coordinated care (Woy & Dellario, 1985). Coordinated care ensures smooth transition of rehabilitation and transfer of client information.

More recently, innovations in rehabilitation programs have attempted to incorporate the need for an extended, coordinated and individually designed treatment (Gobble et al., 1987; Wehman, Kreutzer, Wood, Morton, & Sherron, 1988). McAllister, Rundell, Parker, and Ferguson (1990) describe a comprehensive program design that attempts to

provide a link between traditional medical rehabilitation and vocational services. This program operates with a multi-disciplinary environment, consisting of the medical team and vocational rehabilitation staff. This employment reentry program uses a "case management approach," assessing each client independently for program suitability and attempting to modify activities to meet individual needs. The components of this program include client assessment, cognitive/vocational skills training, work simulation and job try out. Each of these components takes place within the hospital setting.

Wehman and colleagues (1988, 1990) have recently introduced an approach to vocational rehabilitation, specifically in an attempt to meet the diverse needs of persons with brain injury (Kreutzer, Wehman, Morton, & Stonnington, 1988; Wehman & Goodall, 1990; Wehman & Kreutzer, 1990; Wehman, Kreutzer, Wood, Morton & Sherron, 1988). The key addition of this approach in comparison to earlier models is that of supported employment, or job training, while the client is in a work environment. The supported employment approach seeks to help persons with brain injury choose, attain and maintain paid jobs in integrated employment settings through providing them with job placement, job-site training, ongoing assessment and follow-along services provided by a "job coach". The addition of supported employment is designed in order to provide the client with more personal control and support in job choice and decision-making.

Critique of Vocational Rehabilitation Models. The development of vocational rehabilitation models has progressed quite rapidly. At first, limited services were available to persons with brain injury once discharged from the hospital. Their medical and physical symptoms had been dealt with the best way that the hospital environment could provide. Persons recovering from brain injury were then asked to make the transition from institution to community with minimal or no assistance. Few vocational rehabilitation programs existed. Once the problems of community transition and the potential for rehabilitation became apparent, many theories and models were developed in

an attempt to alleviate hardships this transition created. The first program attempts were located within the community. Once the physical problems were dealt with by the medical model, individuals were referred to vocational rehabilitation programs within the community. This model leaves much to be desired and leads to only minimal success for the clients. A major weakness within the traditional model is lack of communication between the persons involved in the medical establishment and those in the community. Further, the vocational rehabilitation process will have a higher degree of success if it is incorporated into other rehabilitation processes. It cannot be just an "add on" once the person has reentered the community. Establishing and maintaining links necessary to provide coordinated care are essential. Fawber and Wachter (1987) stated that many persons with brain injury are either "deemed as unemployable or fail at a placement," not necessarily because they are unemployable but "because they are unable to benefit from traditional vocational rehabilitation services" (p. 28).

Moreover, the traditional linear approach has another inherent limitation. In its progressive stage approach, it requires individuals to generalize and transfer learned skills from one situation and environment to another. This task is one that is most difficult for a person with brain injury and may decrease the likelihood of ultimate success (Fawber & Wachter, 1987; Johnson, 1989; Zahara & Cuvo, 1984). High level thought processes such as convergent and divergent thinking, and deductive and inductive reasoning are subject to disruption after brain injury (Sohlberg & Mateer, 1989). Ben-Yishay and Diller (1983), Goldstein and Lewin (1987) and Prigatano (1986) identify similar deficits in higher level or complex problem solving abilities. These impairments make it difficult for persons with a brain injury to generate hypotheses, employ problem solving strategies and to generalize and transfer learned skills. In addition, "limited consideration of the ecological validity of tasks weaken the chance for generalization of therapy to naturalistic settings" (Sohlberg & Mateer, 1989, p. 289).

Coordinated care must be a major component for any vocational rehabilitation program. Those involved with the medical component are most familiar with the needs and skills of the clients upon return to the community and must remain major proponents in the clients' community transition to foster success. Further, these medical models may be of some detriment to the person recovering from brain injury. By focusing largely on the medical and therapy aspects, persons with brain injuries may experience temporary loss of self, lack of participation in the decision making, and the perception that they are being viewed for their deficits rather than their abilities and strengths.

McAllister et al. (1990) and Wehman and colleagues (1988, 1990) describe a much more comprehensive program design that provides a link between traditional medical rehabilitation and vocational services. Most appropriately, an interdisciplinary approach is advocated. Both writers support an extended, coordinated and individually-designed vocational rehabilitation program. A most accurate assumption implicit in both models is that vocational rehabilitation takes much time and work for all involved. Further, vocational rehabilitation must be flexible, developing components to meet the varying needs of the clients.

The models promoted by McAllister et al. (1990) and Wehman and colleagues (1988, 1990) differ in three important aspects. First, in McAllister et al.'s application, all components take place within the hospital setting. However, Wehman's approach supports vocational rehabilitation in the institution as well as the community. Wehman's approach considers the client's difficulty in skill and knowledge generalization and transformation. Aiding the client in the community environment will further enhance the possibility of attainment and maintenance in employment.

The second distinction between the two approaches relates to supported employment. Wehman proposes an employment specialist or job coach, a person who accompanies the clients in their attempt to implement learned skills, behaviors and work

routines to the environment of competitive employment. Preliminary studies, although few and small in sample size, show potential for this approach (Wehman & Kreutzer, 1990; Wehman et al., 1988; Wehman, Kreutzer, Wood, Morton, & Sherron, 1988).

The two models also differ in their suggested order of rehabilitation. More specifically, McAllister et al. (1990) advocate job training be completed before job placement. On the other hand, Wehman presents an approach whereby clients are placed into competitive employment and then training with follow-along support is provided. In other terms, the former proposes the traditional "train-place" practice while the latter supports the implementation of "place-train". The difficulty of generalizing and transfering learned skills is a paramount consideration in Wehman's decision to conduct the major component of training on-the-job.

Summary

The majority of persons with severe and moderate brain injury remain unemployed (Jacobs, 1988; Haffey & Lewis, 1989). Today, the study of brain injury rehabilitation is moving beyond the developmental stages. In the 1980s many new theories, models and strategies for rehabilitation were presented at conferences, in professional journals, and in texts. A great deal of descriptive literature is available relating to treatment and rehabilitation approaches that are intended to benefit persons with brain injury. However, there is little empirical research to demonstrate the efficacy of these approaches (Veldheer, 1990), although some promising research is emerging.

Many practical applications of the theories and models seem to leave much to be desired. Institutions specializing in developmental disabilities are attempting to serve this population with little or no prior knowledge in brain injury and programs seem to be largely reactive. As well, most of the earlier models are modifications of what has proven effective with other populations, thereby not proven to be of success with persons recovering from brain injury.

Goldstein and Ruthven (1983) emphasize that the present state of knowledge is limited with regard to what is and is not possible for persons with a brain injury and what are the best approaches to their rehabilitation. Kay (1989) argues, "the field of brain injury rehabilitation has been more eager to provide services than to critically evaluate the effectiveness of those services" (p. 159).

The ultimate success of any programing can perhaps be measured by the amount of independence that the person experiences over time and the way in which programs help individuals to improve the control and quality of their lives. By definition, no one in society is totally independent. We all require assistance from others. But, most important, each person is assumed to be in control of his or her life and to be responsible for his or her destiny in terms of making conscious choices, accepting consequences for decisions, and finding the resources required for daily living (Jacobs et al., 1990). Each person with brain injury has unique challenges which present questions about what type of, or how much, support is appropriate to the situation and from where this assistance will come.

The supported employment model is currently identified as the best option. However, it still leaves room for improvement. It is important that the clients themselves are given an opportunity to articulate their views and to express their needs. It is for this reason that this study was undertaken.

Chapter 3

Methodology

The research study questions were answered through a qualitative research paradigm. The researcher utilized a descriptive exploratory research methodology synthesizing the methods used by Colaizzi (1978), Giorgi (1975), Osborne (1990) and Vargo (1983). This research was not intended to test an operationally defined hypothesis, but rather sought to understand individuals with brain injury by allowing them to articulate their experiences.

Brain Injury Development Works Employment Program

This study focused specifically on rehabilitation services in the urban setting of Edmonton, Alberta. Many agencies in Edmonton, Alberta function for the explicit reason of providing vocational rehabilitation to persons with special needs. Only a few of these agencies' vocational rehabilitation programs actually lead to competitive employment and even fewer provide services to persons with brain injuries.

One recent initiative to serve this group of persons with brain injury is BID Works, an acronym for Brain Injury Development: Work Options, Resources, Knowledge, and Skills (Regehr, 1991). This is a partnership program between the Glenrose Rehabilitation Hospital and Distinctive Employment Counselling Services of Alberta (DECSA), a community agency designed to help all persons recovering from brain injury to enter or reenter the work force. BID Works is the only government funded program in Edmonton specifically designed to serve persons with brain injury for work reentry at no cost to the individual.

Funded as a one year pilot project, Bid Works started in March, 1992, and offers vocational rehabilitation intended to meet the specific needs of individuals with brain

injury in the transition from hospital to community competitive employment. Services within BID Works have been designed to assist persons with brain injury in learning or re-learning skills for successful competitive employment. The program is mandated to serve between 12 and 18 clients per year. The BID Works program largely mirrors the model proposed by Wehman and Goodall (1990), incorporating a partnership between a rehabilitation hospital and a community agency to ensure continuity and smooth transition from hospital to community. Job support is provided at all stages of the program, as well as long-term follow-along services such as regular ongoing contact with the client and the employer.

DECSA, in partnership with the Glenrose Rehabilitation Hospital (GRH), coordinates the BID Works program. The two BID Works staff members that coordinate the program and provide vocational counselling and job coaching are employed by DECSA. These BID Works staff members specialize in working with persons recovering from brain injury to identify barriers, identify vocational needs, plan vocational goals, and provide job coaching and support toward successful employment.

The length of intensive involvement in the BID Works program varies according to the needs of the client. Most clients are involved in the BID Works program for three to four months before attempting to work independently in a competitive work placement. Participants may take part in any or all of the BID Works components in the most suitable sequence, although the presentation order outlined below is usually considered the most appropriate.

The BID Works' program components include vocational counselling, in-hospital volunteer work assessment, employment support group, and community work trial leading to paid competitive employment. More specifically, the BID Works program is structured as follows:

1. Referral - Referral to BID Works is initiated by a treatment team member in the Brain Injury Rehabilitation Program at the Glenrose Rehabilitation Hospital. The process is designed to ensure that participants have the benefit of rehabilitation support and intervention prior to making the transition to involvement in a community service (e.g., physical rehabilitation, psychological or substance abuse counselling). Referral and intakes are accepted throughout the year. The number of referrals received by BID Works each year varies according to community need.

2. Intake Interview - An interview is conducted with participants for the purpose of clarifying the following points: general program information and available services; program and participant expectations; participant employment/training goals and interests; and participant concerns or issues regarding return to work. As well, the client's program component needs are assessed (i.e., most appropriate work experience, rehabilitation to pre-injury job) and an attempt is made to meet the client at his or her present functioning level (participation in all components may be unnecessary for some clients).

3. Vocational Counselling - BID Works staff assist participants in choosing realistic vocational goals through individual vocational counselling. Participants are aided in identifying and balancing lifestyles/vocational likes, dislikes, needs and skill levels and in making realistic decisions about type of work and work environment. The goal is to assist participants in making healthy choices for satisfying vocational involvement. Vocational counselling is ongoing throughout the client's involvement in BID Works.

4. In-Hospital Volunteer Work Assessment - This experience provides participants an opportunity to test work abilities and identify work needs, to try jobs simulated as closely as possible to "real work situations," and to benefit from full support to begin dealing with issues that may pose barriers to ongoing community employment. All work

assessments are volunteer and structured on a part time basis (i.e., 3-4 hours per day, 5 days per week)

This volunteer work assessment comprises a four week, half-day placement at the Glenrose Rehabilitation Hospital, supervised and supported by BID Works staff (length of time may vary based on client needs). Work location is matched as closely as possible to the client's vocational goals identified during the initial interview and the counselling procedure. If no appropriate placement can be obtained within the Hospital, the volunteer work assessment may be conducted in the community.

5. Employment Support Group - Through group discussion, feedback sessions, information presentation, role play, video and written exercises, participants deal with issues relating to job attainment and maintenance including: work behaviors, work expectations, conflict resolution, work supports, resume writing, interview techniques and job search information. One goal of the support group component of BID Works is to strengthen the individual's overall ability to recognize and deal effectively with work issues for community placement.

The second goal of the group is to provide a medium whereby participants, along with support members, can develop and/or expand their social network and acquire the support needed to deal with issues related to vocational involvement. The support group runs one evening per week for a duration of two hours. All clients are required to come to six sessions where the above topics are addressed. After this time, attendance is voluntary.

6. Community Placement Services

Community Placement Services consists of two parts:

a) Community Volunteer Work Trial - The work trial facilitates the transition from volunteer work to employment in the community. Community work trials, lasting an

average of four weeks, offer job and training supports by the BID Works staff. The level of support is gradually phased out as participant independence and skill levels increase. Work trials include work evaluation and ongoing assessment of work behaviors and skills. Work trials provide a vehicle for identifying needs related to future employment, on-the-job training, more formal training, treatment and/or other community service alternatives. The goal of the community work trial is to lead directly to ongoing paid community work with the same employer. Those participants with identified formal training needs will be supported in realizing educational goals.

b) Paid Work Placement - The paid work placement is viewed as an extension of the community work trial. The participants will be paid for the work done (placements continue with the same community work employer). Job support services will be extended to meet ongoing on-the-job training needs.

During both community volunteer work trials and paid work placements job coaching is provided. Once a client is placed, trained and working without the need of daily intervention in the competitive placement, a minimum of six months follow-along is provided to ensure job maintenance. This follow-along service includes regular ongoing contact with the employer and the client and the option for either to contact BID Works staff at any time if problems or difficulties occur.

Participants

At the time of the first interview (September, 1993), 14 clients had completed at least half of the BID Works vocational rehabilitation program. Of these 14, two had moved with no forwarding address or phone number, two declined to participate in the study, one client did not remember having participated in the rehabilitation program, and one participated in the pilot study. Therefore, the researcher interviewed the remaining eight clients for this study. The selection criteria for entry into the program were that participants must be 18 years of age or older, display a willingness and motivation for

program involvement, and have competitive employment as a realistic long-term goal. The participants were chosen because of their desire to return to competitive employment in the community and therefore were felt to have the most insight into the difficulties and challenges attempts at work reentry represents.

The final sample comprised individuals with a range of characteristics, with differing severities of injury as measured by the length of coma or loss of consciousness (LOC) and post-traumatic amnesia (PTA), and differing lengths of unemployment. They therefore represent a wide range of perspectives held by persons with brain injury with regard to work reentry. Further, participants wanted to participate in the study, had the time to devote to the interviews, had held at least one job prior to injury, sustained the injury during late adolescence or adult years (16 years of age or older), and were willing and able to clearly articulate their experiences and feelings. All participants had been judged to have recovered sufficiently to be involved in a vocational rehabilitation program, as assessed by the treatment team at the Glenrose Rehabilitation Hospital (GRH).

Medical records were reviewed by the researcher and a clinical neuropsychologist and the following information obtained. Post-traumatic amnesia (PTA), or amnesia, levels were available for 5 of the 8 participants, with a mean level of 47, 232 minutes (787.2 hours, 32.8 days). Determining the severity of the brain injury based on PTA levels (Jennett, 1990), a further breakdown revealed: two participants were regarded to have an extremely severe brain injury (PTA of more than 4 weeks); three participants were regarded to have sustained a very severe brain injury (PTA of 1 to 4 weeks); one participant sustained a severe injury (PTA of 1 to 7 days) and, two participants were regarded to have sustained a moderate brain injury (PTA of 1 to 24 hours). (A clinical neuropsychologist familiar with the three respondents whose files were incomplete

determined the severity of the injury for categorization in this research study). The mean age of the respondents was 36.6 years, with a range of 23 to 55 years.

The mean length of unemployment after brain injury was reported at 56.8 months, with a range from 18 to 144 months. The sample comprised two females and six males. The brain injuries were sustained through two main means. Five respondents sustained their injuries as a result of motor vehicle accidents and three participants received their injuries following complications associated with aneurysms. Detailed data concerning each participant are presented in Table 1.

Table 1.

Descriptive Data

Participants*	Length of Coma	PTA** /Amnesia	Age (at time of study)	Months since Injury	Length of Un-employment
Anna	Unknown	Unknown	38 years	44 months	18 months
Bob	720 min.	4320 min.	44 years	60 months	60 months
Carl	Unknown	Unknown	39 years	84 months	60 months
Don	Unknown	30, 240 min.	23 years	35 months	29 months
Ed	25,920 min.	80,640 min.	37 years	228 months	144 months
Fred	2,160 min.	40, 320 min.	25 years	48 months	36 months
Greg	20,160 min.	80,640 min.	32 years	79 months	79 months
Helen	Unknown	Unknown	55 years	37 months	28 months

* Names have been changed to protect the identities of the participants

** PTA = Post-Traumatic Amnesia

Interview Guide Development and Pilot Study

Once the participants for this study had been determined from the BID Works program, the researcher completed a draft interview guide using the information gathered

from the literature and personal expertise in the field. This draft was presented to the thesis supervisor for refinement and approval.

Next, one client with a brain injury meeting all of the outlined criteria for participation was chosen for the pilot interview. The researcher conducted the interview and discussed possible refinement and further questions/probes with this. Results obtained from the pilot study were not included in the final sample. The pilot interview proved valuable in three areas: 1) refinement of the interview guide, 2) refinement of the interview process, and 3) insight into the nature and quantity of data which might be expected from subsequent interviews (Vargo, 1983). Questions were clarified and reordered for more precise interpretation and expression of research goals.

Results of the pilot study were presented to the committee members and further refinements conducted. This process was completed in August, 1993. The interview questions and protocol were then written and utilized in all subsequent interviews with the participants chosen for the study. The interview focused on three broad areas: general factors aiding in, and barriers to, returning to work; beneficial and negative factors of the vocational rehabilitation experience; and additions and improvements to vocational rehabilitation programs (see Appendix A).

Data Collection

Each participant was interviewed individually in September and October 1993, using the semi-structured format. Interviews were conducted at the location chosen by the participant. Most chose their home, stating that this environment was most comfortable for them. All participants were fully informed of the nature of the research, and asked to sign a consent form (Appendix B). Each interview lasted between two and two and one-half hours with no interruptions. No other people were present. All interviews were tape recorded and transcribed. Tapes were erased after transcription.

A second discussion was conducted with each of the participants in February and March, 1994, in order to validate and verify the results of the data analysis. Each participant was given the opportunity to read through their respective transcripts and provide feedback and comments. Written records of comments and changes were maintained by the researcher during the second interviews.

Data Analysis

A step-by-step analysis of the data was conducted using a synthesis of methods from research studies conducted by Colaizzi (1978), Giorgi (1975), Osborne (1990), and Vargo (1983).

In Step One, the researcher repeatedly reviewed the transcripts to become acquainted with the data.

Step Two involved a sentence-by-sentence analysis of the transcripts. During this step, each participant's responses were reduced to paraphrases. This ensured that the meanings expressed by the participants were retained. The ideas of each paraphrased sentence was then interpreted and written down. Next, similar essential ideas were clustered, or placed into groupings. These common ideas were given a theme name, thereby groups were filed into higher order clusters. This step resulted in a hierarchical structure with different levels. Lower level clusters were subsumed by higher level clusters. The hierarchical structure in its entirety eventually comprised the clusters of themes that described the individual's articulated experience. In a sense, this stage of analysis approximated a "within-persons" analysis (Osborne, 1990). In within-persons analysis the focus is on the individual.

The next step, Step Three, involved a comparison of the thematic clusters in order to extract shared themes, or commonalities across individuals, from the individual thematic analysis conducted. In this step the final thematic clusters for each person were

compared in order to identify shared themes. In other words, the objective of data analysis was to identify common themes that individuals expressed or articulated. This stage of analysis approximates a "between-persons" analysis (Osborne, 1990).

In Step Four, the researcher referred back to the original responses and compared them with the identified themes in Step Three to ensure validity and correct clustering.

In Step Five, themes were divided into major and minor emergent experiences. An experience was defined as a major theme if at least 50% ,or 4 to 8, of the interviewees expressed the same idea (Vargo, 1983). A minor theme was one that at least 30% and less than 50%, or 3 of the participants, identified. For parsimony, the major themes were categorized into super-ordinate or overriding themes. This ensured the data were retained, but facilitated interpretation and presentation of results.

In Step Six, the researcher met with the participants for a second interview. They were given the opportunity to read through their transcripts derived from the first interview. As well, each individual was asked about themes that he/she did not allude to during the original interview. This was done to ensure that any omissions were a valid representation of the participant's experience, not because the issue was forgotten or avoided. As well, participants were asked if they felt comfortable with their component of the Introduction to Participants section of chapter 4. All responded positively. Step Five was then repeated to include any new information obtained.

The end product of the data analysis was a comprehensive analysis of the participants' experience that was placed in conceptual and theoretical language. In other words, the objective of the data analysis was to elucidate the deeper structures of meaning that underlay the responses of the participants. In presenting the results, direct quotations are used as exemplars of each theme.

Validity

Validity of the research was established through three primary means, as discussed by Osborne (1990). First, the procedure for data collection and the process of interpretation was carefully documented and presented in the thesis. By providing the reader with the opportunity to understand the interpretations presented, the reader can accept or reject these interpretations (Giorgi, 1975). Second, following initial analyses, the researcher presented the results to each of the participants for his or her inspection and verification. Ensuring dialogue between the participants and the writer enables a check of the "congruity of the interpretations with the participants' accounts of their experience'" (Osborne, 1990, p. 20). Third, "the most crucial means of validating interpretations of ... data is the juridical process of presenting coherent and convincing arguments" (Osborne, 1990, p.20) The researcher attempted to allow interpretation to emerge logically from the data, be presented clearly and defended well.

Reliability

Quantitative notions of reliability including consistency, replicability and stability, are not generally applicable to qualitative research. In qualitative research, reliability is based on the perspectives and perception of the participants whose experiences are contextualized. It is possible that there can be more than one perspective on the same experience. However, "sameness" or "trustworthiness" (reliability) arises out of the inconsistency, variability and relativity of human perception. The basis of social reality (common sense) is intersubjective agreement " (Osborne, 1990, p. 18).

In addition, qualitative researchers note the difficulty of separating the constructs of reliability and validity since one presupposes the other (Wertz, 1986). Thus, the primary threat to reliability and, thereby, validity lies in the interpretation of the data. There is no single correct means of interpreting raw data and ambiguity is "intrinsic to meaning" (Osborne, 1990, p. 19). This study attempted to present the data and defend

interpretations through logical and well reasoned thought, supporting interpretations through use of the raw data.

Limitations and Delimitations

Limitations. Limitations to this research study were identified. Though these were not under the researcher's control, they must be considered in the final data analysis and implementation. First, the respondents were drawn from one small group. This will affect generalizability. The agency that participants were drawn from was located in Edmonton, Alberta, and was the only specialized brain injury work reentry program in the geographical area. However, qualitative researchers conceive of generalization differently than do natural science researchers (Smith & Glass, 1987). Thus, the extent to which the results of this study may be generalizable will depend on logical analysis of the similarities and differences between the sample chosen and other groups, and not on statistical notions of representation of a defined population (Smith & Glass, 1987). It must also be mentioned that the researcher was a BID Works staff member before this research study was conducted and therefore had a professional relationship with most of the participants prior to conducting this study.

Further, the participants were in different stages of the program. Most had already completed the program, while others had just completed the in-hospital work placement. Moreover, participants had gone through various stages of rehabilitation before having been referred to BID Works. Some had been referred directly from their acute care setting, while others had been in the community for many years post-injury. As well, some participants had been involved in other work reentry programs not specifically designed for brain injury. In sum, the persons recovering from brain injury that seek help in returning to competitive employment are a varied group, ranging from moderate to severe injury, and varying severity of long-term cognitive and physical effects.

Though one can state that the target population was all persons with brain injury who aspire to competitive employment, this qualitative study does not assume generalizability of results to all of these individuals. Despite some loss of breadth and generalizability that arose from the use of a small sample, the study gained greater depth of understanding of the specific phenomenon in review (Borg & Gall, 1989).

Delimitations. Those who were chosen for participation in this study had to be motivated to participate and have the time to complete the interviews. Furthermore, participants in the study had to be able to articulate, i.e., express themselves verbally, due to the interview format chosen for data collection. They had to have received their injury post-puberty (age 16 or later) and have held at least one competitive job prior to injury.

Ethical Considerations

Ethical guidelines were strictly adhered to in conducting this study (University of Alberta, 1991). Research participants were contacted, given full details about the nature of the study, and asked whether they wished to participate in the research study. Written voluntary informed consent was obtained from all participants (see Appendix B). Individuals were also informed that they could withdraw from the study at any time if they wished. All participants were guaranteed confidentiality. All information was used solely for research purposes and all identifying information was removed from the documentation. For example, the participants were given first names unrelated to their real names and any information that may have linked an individual to the research was eliminated in the final presentation of data.

Chapter 4

Presentation of Results

This study examined factors affecting return to employment from the perspective of people who had sustained a brain injury, and explored ways to facilitate and improve their rehabilitation process. Information was obtained from participants through a semi-structured interview which comprised nine questions. This chapter introduces the eight research participants. Next, major and minor themes identified through content analysis are presented and discussed. Quotations exemplifying each theme substantiate the participants' experiences. The chapter is organized according to the interview questions, as outlined in Table 2. Although the original interview guide included 9 questions, the data are presented within 5 sections. Where responses overlapped they were combined in the most appropriate sections. For example, the responses to questions dealing with additional comments were included with suitable earlier questions. Major themes are also grouped according to super-ordinate, or higher level, clusters for parsimony. Minor themes, those themes represented by 3 respondents, are noted.

Table 2

Number of Themes per Interview Question

Question/Topic	Themes	
	Major	Minor
Introduction to Participants	-	-
Barriers to RTW *	8	3
Aids to RTW*	5	0
Beneficial Factors of Voc. Rehab.**	4	2
Negative Parts of Voc. Rehab.**	2	3
Suggested Additions/Improvements	10	4

* RTW = Returning to Work ** Voc. Rehab.= Vocational Rehabilitation

Introduction to Participants

The first question asked the participants to introduce themselves and to describe, in general terms, their experience in trying to return to work after sustaining a brain injury. This introduction serves as a reminder of the unique nature of brain injury and emphasizes the devastating impact such injuries have on peoples' lives. As discussed in chapter 3, all of the eight clients felt comfortable with the information presented below, and confident that this did not infringe on their confidentiality.

Anna. Anna is tall, direct, in her thirties, and a single mother who lives independently with her child. Anna was flustered at the beginning of our visit because of an impending move. She described this as a difficult and frustrating process. Anna is a sociable person who speaks her mind. Approximately three years ago she experienced an aneurysm. Surgery was needed to stop the bleeding. She was released from the hospital to her mother's care. Once she became stronger, she moved back to her own home with her child. BID Works is the only community rehabilitation program that Anna has been involved in. She was rehabilitated to return to her pre-injury position. Unfortunately, her union would not allow BID Works to provide on-the-job supported employment on site. Therefore, she was provided no assistance on location when she started back to work.

Anna's most difficult factor to deal with as a result of her brain injury is loss of self-confidence and her emotional guard or defenses (i.e., she may cry uncontrollably at inappropriate moments). This loss makes all social situations extremely difficult for her.

Bob. Bob is a single male, in his forties, living in the home, and with the aid, of his elderly mother. Like Anna, Bob also suffered an aneurysm. The aneurysm was too deep, however, to be treated surgically. Pre-injury, Bob had been working in a number of management positions. This man is unique to this study, because he has the most severe cognitive deficits as a result of the brain injury. He has been involved in three different community work re-entry programs. BID Works is the most recent.

Bob stated that "when I got out of the hospital there was no pain with this, there were no physical effects, ... it was like I don't have this brain injury ... I was normal." Part of him continues to believe that he will be "normal" again in time.

Carl. Carl is a man of few carefully chosen words, who lives with his mother. Carl is divorced, in his thirties, and a father of two. Because his children live in a neighboring province, he is unable to visit them very often. Carl had a motorcycle accident a number of years ago. Prior to his injury, he was a trades person, but has not competitively worked in his trade since his injury. Carl is unique to this interview study because he has, in a three year time period, participated in four community vocational rehabilitation programs. He applied to a fifth, but was refused. Most recently, he has been involved in BID Works.

Carl believes that people do not know much about brain injury and its effects on the individual. He includes staff in rehabilitation programs and people in the community in this statement. Although this knowledge has been increasing slowly, Carl was one of the first "brain injured" clients in local rehabilitation programs. He stated that rehabilitation has been a slow, painful process and, even though his injury was over 7 years ago, he believes he is not at the end of the process.

Don. This athletic looking single young man in his early twenties enjoys weight lifting and going out with his buddies. Don is very polite, quiet and a little shy. Prior to his brain injury, he was a full time student in high school and had worked part-time in a number of labor positions. Don had a motor vehicle accident and, since that time, has been involved, to varying degrees, in both physical and cognitive rehabilitation. He is currently involved in litigation over his accident. This person is unique to the interview group because he has the most recent injury and is also the youngest participant. BID Works is the first community work reentry rehabilitation program that Don has been involved in.

In discussing his experiences since his injury, Don stated, "I really didn't look that hard for a job in the beginning. I was trying to get my life together again, just trying to figure out what I need, what I want."

Ed. Ed lives in a community just outside of Edmonton with his sister, her husband and his teenage niece. Ed is an extremely polite, thoughtful and kind man. This man is tall, well built, single, in his thirties and walks with an uneven gait. Though his speech is slightly slurred, he accommodates by slowing his speed and pronouncing words with precision, making his conversation clear and understandable. Ed was involved in a motor vehicle accident. Prior to his injury he was a motivated student who obtained top grades. In addition to attending school, he worked part time in a number of labor jobs. Ed has the distinction of having a brain injury longer than any of the other participants (over 20 years) and of receiving the injury at a younger age than others in this study (in his late teens). He has been involved in three community work reentry programs, with the most recent being BID Works.

Ed has come to believe, through his experiences, that motivation and determination are key factors in getting and keeping a job. He felt he had lost jobs because he had neglected his duties, came to work late, and did not care enough to perform to his full potential.

Fred. Fred is a determined and motivated man, who is very polite and a little shy. He is single and in his twenties, living between two homes--one with his parents and the other with his sister and her husband. Prior to his injury, he worked as a laborer. Fred was completing further education in the evenings in order to be promoted to a trade worker. On his way home from work one day he was involved in a motor vehicle accident, resulting in a brain injury. After most of his physical rehabilitation was completed, he continued his quest to complete qualifications (education and work experience) in his chosen trade. Fred is unique to this study because he has successfully

continued post-secondary education post-injury. He was able to do this through much personal motivation, determination and a trade school with understanding instructors.

Fred believes he has learned how to persevere and follow through with whatever needs to be done to reach his ultimate goal, a job in his trade. Toward this end, Fred has volunteered many months of free labor to gain experience and certification.

Greg. Greg is a tall, single young man in his early thirties. Because of a strong accent, it was apparent that he is a recent immigrant to Canada. English remains difficult for him. During the interview he stated that he has difficulty finding the right words to express himself. The meeting took a little longer with much questioning and rephrasing to make sure that the researcher had understood him correctly. Greg received his brain injury as a result of a motor vehicle accident. He lives in his own apartment and receives support from his family. This is the only participant who was not yet in the last phase of the BID Works program. BID Works is the only community rehabilitation program in which he has been involved.

Greg wanted to make sure that people understood his belief that persons who have sustained a brain injury differ in many respects. He maintained "people are very individual, they have some of the same experiences in 'coming back,' but they will not be the same, the injury is different, the people with brain injury are as different as normal people."

Helen. Helen is a petite woman, divorced and in her fifties. Although seeming timid and soft, her spoken words were well chosen and direct. She lives independently and when requiring help, has family members and a few close friends in the area. She is outspoken and able to identify positive aspects in difficult and trying circumstances. Helen experienced an aneurysm and, as a result, underwent two brain surgeries. Different from the other interviewees, she frequently used metaphorical and abstract speech. In

returning to work, she believed that "when you can see the pot of gold at the end of the rainbow, then you have already succeeded, in fact you can enjoy the scenery."

Barriers to Returning to Work

The second question asked participants to identify the factors that hindered their attempts to return to work. Two super-ordinate themes (cluster titles) were identified: understanding of self and work related factors. Eight major and four minor themes emerged. These are represented in Table 3. To reiterate, themes raised by 4 or more participants (at least 50% of respondents) were considered major. Themes raised by three participants (between 30 - 50%) were classified as minor.

Table 3
Barriers to Returning to Work

	Cluster Title	Theme Titles	# of Responses
Major themes			
	Understanding of Self		
		Effects of the Brain Injury	8
		Change of Life	8
		Self-Esteem/Self-Confidence	6
		Acceptance of the Effects of the B.I.*	5
	Work Related Factors		
		Premature Work Readiness	7
		Depressed Economy	6
		Employer Knowledge	5
		Lack of Experience	4
Minor Themes			
		Lack of Education	3
		Poor Job Performance	3
		Feeling Lost/Directionless	3

* B.I. = Brain Injury

Understanding of Self. Changes in the "understanding of self" were perceived by all participants, although the specific meaning of these changes were multifaceted. Central to notions about self were the themes of the effects of the brain injury, changes in life, difficulties accepting these effects, and changes in self-esteem or self-confidence.

Theme 1 - Effects of the Brain Injury. All of the participants mentioned the cognitive effects of their brain injury as major hindrances in attempting to return to work. Each injury is different and therefore the particular facets of those effects vary for each participant.

> How can I learn, how can I get work and earn money if I can't concentrate on something?
>
> Sometimes the biggest disadvantage is that I have long-term memory. It would be better having lost long-term memory. (Can you help me understand that?) Because I know who and what I did and what I was capable of and that's not good.
>
> I don't have the agility anymore, I'm not graceful, ... balance, if I lean over I feel myself falling, ... coordination, sense of balance, equilibrium.
>
> (C)an't think as fast or work as fast, but if I take my time I can usually work my way through it.

Theme 2 - Change of Life. All eight participants stated that they are now "different"; their lives had been radically changed. One stated, "Now I am different, not normal suddenly." Another felt, "You are never the same, everything is different." A third commented, "I want to be someone again - happy, confident, weird, smart, I want to be me again."

With the exploration of the changes within the participants' lives, pre-injury vocational goals were often deliberated and reconsidered. This re-evaluation led some participants to pursue the same career as pre-injury and others to chose new career paths as part of this change of life. However, this acceptance and understanding of life change does not happen without confusion and anger.

> You want to give me something, and I ask something. I just want to get back to work and get a job and have (everyone) leave me alone. That's what I want--to get to a normal life and stop with the brain injury.

One participant, who had experienced anger earlier in her recovery and now has successfully returned to work, stated:

> I want people to know that you can come out of this and still be who you were, but just different, ... the self-acceptance was the hardest part, to say, 'OK, I used to be like this and am now like this', that is the hardest part to do.

Theme 3 - Self-Esteem/Self-Confidence. The actual effects of the brain injury and events post-injury is perceived to be responsible for low self-confidence and low self-esteem as expressed by 6 of the participants. Representative quotes are:

> I tried to work on my self-confidence and my self-esteem...I believe that my self-confidence has gradually gotten more esteem and has become stronger throughout the years.

> Oh, you bet it (the injury) did (affect my self-confidence). Other people have mentioned that, too They are right, that is one of the biggest things that you need back. It has to be something that I can feel comfortable with and that is not a real low level.

Theme 4 - Acceptance of the Effects of the Brain Injury. In addition to listing the actual effects of the injury and the ensuing lowered self-confidence and self-esteem, 5 participants commented on their need to accept the effects of the brain injury. Through acceptance of the injury, they were more likely to accept themselves.

> The acceptance has been made. The self-acceptance was the hardest part, to say ok I used to be like this and am now like this, that is the hardest part to do, it's the acceptance and a lot of people don't accept themselves.

> Acceptance and understanding (of the effects of the brain injury) surely affects my return to work. I thought, its gonna go away and I'm gonna get better, I'm gonna be...like before.

Work Related Factors. The second broad cluster within the area of barriers to returning to work dealt specifically with work related themes such as work readiness, employer knowledge levels, the depressed economy, and lack of experience.

Theme 5 - Premature Work Readiness. Seven of the eight participants stated that for a period of time directly after the injury and once released from the hospital, they perceived themselves ready to return to work. However, in retrospect they realized that

they had not been ready to return to work at that time. The rehabilitation process, for them, had only just begun.

> Well, I wanted to go back to work right away actually, not knowing that ... I wasn't capable, mentally capable, but I wanted to go back right away.
>
> I was pushing the doctors to let me back to work, because I had an interview with (name)...I really wasn't up to par at that time, because simple questions about (basic trade knowledge) I could remember doing it but can't remember how, can't remember the formula. Now I wish I could do the interview again.

Often people with brain injuries only discover through time the cognitive difficulties that result from injury. It takes time to recognize strengths and learn compensation techniques for weaknesses.

Theme 6 - Depressed Economy. Not surprisingly, 6 of the 8 participants mentioned the present economy as a major hindrance in returning to work. The 2 participants who returned to pre-injury positions did not comment on this.

> (U)nemployment is quite serious these days. There are a lot of people out there looking for work.
>
> Definitely the economic climate would be number one. It's not like the old days where you could go out and grab a job.
>
> (T)here are thousands of people out there who are out of work and who themselves are out there looking to taking a job that pays less money or is moving ... down. I'm in the same boat, but for me its permanent and for them it may be more in the interim.

With high unemployment, finding work is difficult. Employers may be reluctant to employ people who may require extra considerations, and may not be willing to "take a chance" on someone that has an employer imagined or real disability. One participant felt that he was not hired, and another felt he was laid off because of revealing brain injuries to employers and both stated that they would not inform future employers of their injuries.

> None of my employers knew of my injuries (only potential employers where I did not get hired). I'm not going to tell them.
>
> I also learned in interviews, don't tell them more than they ask, because I think that I had a job and lost it when I started talking too much (told them of the brain injury).

Theme 7 - Employer Knowledge. Five participants felt that they would not have been hired or been able to maintain their present jobs without an understanding and knowledgeable employer.

> Well, there is not a whole lot of knowledge around brain injury patients. I think that many employers are paranoid about hiring someone after a brain injury, so its a slow process (to teach them).
>
> It is a good idea for employers to know about brain injury and be supportive. Because a previous employer didn't understand I lost my job.

In light of an apparent lack of knowledge and understanding concerning brain injury, people with this injury face additional barriers to competitive employment. Again, employers may be hesitant to hire any person with real or employer imagined disabilities--most of this is because of ignorance and a lack of understanding about brain injury and its effects. As discussed earlier, the current economic situation makes it even more difficult for persons with some recognized limitation to be given an opportunity to work, regardless of the actual impact this limitation may or may not have on work performance.

Theme 8 - Lack of Experience. Four of the participants expressed that lack of experience was a hindrance to returning to work. In particular, one person, unable to return to his pre-injury trade, felt he had lost years of experience and had only minimal non-paid practical experience in his new area of work. Not only do some individuals feel they have lost years of valuable experience, but they are forced to start all over again in the work force, often competing with younger and more experienced workers. Comments include:

> (I)t's the people that aren't qualified (through work experience) that have the problem competing.
>
> Definitely a lack of experience (is a hindrance).

Minor Themes. Minor themes identified with respect to barriers to return to work included lack of education, poor job performance and feeling lost or directionless. With respect to education, it was believed that jobs required training, knowledge of computers

and more than grade 12. This may be a particular impediment because persons with brain injuries often report memory difficulties which makes complex learning and formal education very difficult, sometimes impossible. In addition, poor work performance has caused difficulties in maintaining jobs. This was mentioned by three participants who tried to reenter the work force without supported employment. Lastly, participants reported feeling lost and directionless. One person stated, "I do not know what I like at the moment. I do not know what I am able to do, you know what I mean. I don't know."

Factors Aiding in Returning to Work

The next question in this study asked about factors that helped participants in their attempts to return to work. Table 4 outlines the themes and frequencies by two broad clusters, one dealing with supports and the second relating to personal attitude.

Table 4
Aids to Returning to Work

	Cluster Title	Theme Titles	# of Responses
Major themes			
	Support		
		Family Role	8
		Other Supports	7
	Personal Attitude		
		Motivation to Return to Work	8
		Involvement in Formal Rehabilitation	8
		Readjustment of Vocational Goals	4

Support. The support offered by family, other persons recovering from brain injury, and rehabilitation program staff was identified as a major factor facilitating return to work.

Theme 1 - Family Role. The role of the family, in particular, was mentioned by all of the interviewees as one of the most important factors in their lives.

> My family helped me because they didn't put me away or something, I don't know how I can explain that to you. They still accepted me, they wanted to help.
>
> I also had the support of my son, that's the only reason I am here. If I wouldn't have had my son, the way my life was going at that particular time, I might have just said, "I'm out of here".
>
> My family was supportive like they were kind of accepting, whatever speed I did things.
>
> The family has been great. They tried to understand when I first came out of the hospital and they are hopeful for me, like that I can get into something that I can do.

The importance of the role of the family should not be underestimated. Research confirms this. Of these eight people, seven lived with and were taken care of by family members after being released from the hospital post-injury. Only three participants did not live with family members at the time of this study. The support families provide extends beyond mere physical needs to the provision of emotional support for those learning to live with a brain injury. In the latter part of the process of reestablishment into society comes competitive employment. Again, the participants identified the family as one of the primary support systems in this process.

Theme 2 - Other Supports. In addition to the family, seven participants credited other peers in the program and rehabilitation staff as playing a major role in their lives in attempts to return to work by providing much needed and appreciated personal emotional support.

> I had a fair bit of support from everybody involved.
>
> The other thing is (a social support group). This gives me a chance to talk to other people (who have experienced a brain injury). When I'm sitting in that group, I'm not the only one with a brain injury. There is no pressure. It makes me realize that, hey, maybe I'm not as bad off as I could be. That there are people with greater problems than I have, and I look at myself and I'm thankful for what I am.
>
> May I say that I found the people I've worked with (the support workers), some of them, to be understanding and very kind hearted workers, very supportive, that was one of the good points.
>
> I like to be around my own kind (support groups) ... we have similar problems, similar handicaps.

Most interviewees did not talk about the support from their friends. Most have lost many of the friends they had prior to their injury. In addition to the family, support is

perceived to come from rehabilitation workers and other persons recovering from brain injury in the form of, for example, support groups.

Personal Attitude. A number of personal factors influenced these individuals' return to work, including motivation to work, involvement in formal rehabilitation, and readjustment of pre-injury vocational goals .

Theme 3 - Motivation to Return to Work. All participants commented on their personal desire and motivation to return to work. One participant believed:

> Who can live a human life without work? Let's say I am not working, how can you have a family - let's say a wife and children - a family without working. You cannot. (I) can't imagine my life without work.

Life without work is hard for many to imagine. Culture mores and imperatives provide a powerful reason for this. Competitive employment is seen by many recovering from brain injury as the last stepping stone in returning to "normal", re-establishing their work role in their community. Participants felt that personal strength and motivation got them to the point of attempting to return to competitive employment.

> Some things I have to be prodded to do because its easy not to have to do something, get afraid, it's easy to go home, not to do it, but I can't, because I know the next day I will go back, I have done most of it and the next step is not as bad and the next step is not as big.
>
> The thing that has helped me the most is my attitude. I believe in myself and I believe in my work. I did lots of things on my own and worked hard...Many people said to me that you won't be able to work any more in your occupation and you are really disabled or something. Those kinds of things also helped me a lot because I would fight against it. I fight.
>
> I work hard, work as fast as I can and try to do a good job. I have a strong desire to work.
>
> It's my drive and my determination and willingness and the fact that I had one (drive), you know what I mean, that was quite a bit, that was the major part of it, I knew I was going back to something.
>
> Every day I try harder to get better, I really try. Ok, I know that was easy before my accident and I want to be able to do it again and I try hard and it will.

Participants were united by their reasons to continue to struggle against the many artificial and real barriers to achieve productive and meaningful lives.

Theme 4 - Involvement in Formal Rehabilitation. Involvement in formal rehabilitation has been a positive factor in eight participants' attempts to return to work.

> The structure (of rehabilitation) ... It's the fact that I had to be there, somewhere, it felt like I was being useful. That helped me get back to work. Also that I had some kind of training course.
>
> The rehabilitation programs I have gone to have been positive because they opened my eyes up.
>
> They are all learning experiences ... It is a learning process.

All participants saw the program(s) as learning experiences which could improve themselves and their present circumstances and seemed uniformly grateful for the opportunity to participate.

Theme 5 - Readjustment of Vocational Goals. While work was seen as very important to these respondents, in order to achieve this, vocational goals needed to be modified. All of the interviewees had at least one job prior to their injury. They were adults at the time of the injury. For most people, vocational hopes and plans had been or were being established by this time. People identify themselves with their occupation. Many of the people who have sustained a brain injury have had to change their career. Often these new careers could be considered to be less skillful, or of lower status and, more often than not, with less monetary rewards. This is, by no means, an easy task for individuals to accept. However, it was one that 4 participants felt needed to be made in order for them to be able to return to the work force.

> I didn't even think that I would ever give up (my trade) ... That was a big switch for me, just thinking about working in a different area. (I went through) a lot just to mentally make that switch. It's not easy, it's been a lot of years. You've just got to keep looking at the positives and keep going.
>
> I've reached a level now that I'm not going to be looking to be way up kind of thing, I'm not looking to be a (manager). I know that I have to start at a lower level. Let's face it, an (entry level job) kind of thing, but I can't right now, just go out and think that everything is going to come back again.

Beneficial Factors of the Vocational Rehabilitation Experience

In question 4, participants were asked to talk about the positive or beneficial factors of their vocational rehabilitation experience. Table 5 outlines the cluster titles and the themes and frequencies within major and minor themes.

Table 5
Beneficial Factors of Vocational Rehabilitation

	Cluster Title	Theme Titles	# of Responses
Major themes			
	Interpersonal Awareness		
		Feeling Productive	8
		Id. * of Personal Strengths & Limitations	8
		Increased Self-Confidence	7
	Socialization and Support		6
Minor themes			
		Individuation of Program(s)	3
		Long-Term Follow-Along	3

* Id. = Identification

Interpersonal Awareness. Three of the identified beneficial factors of returning to work have been clustered under the title of Interpersonal Awareness. Identified as central issues to this growth and self understanding were feelings of productivity, identification of strengths and limitations, and increased self-confidence.

Theme 1 - Feeling Productive. All 8 individuals talked about the vocational rehabilitation program(s) helping them feel productive again by providing direction and structure to their lives and the opportunity to participate in something useful again. (As discussed earlier, all interviewees had participated in at least one job pre-injury, and several had participated in more than one vocational rehabilitation program post-injury.)

> It helped me here to go out and start to do stuff. First when I came here I was happy to be able to go out and to be somebody, and somewhere, not just at home and sitting, and to go out for exercise and something. I was happy to be out and to listen and to try and understand.
>
> Before, it felt that my life was just one big day, or a big week, a year. The program provided some kind of direction, structure ... I was using (the program) as a stepping stone.
>
> I was out getting involved again, doing something, seeing that I was contributing with whatever job it happened to be and, lets face it, just getting out of the house and doing something.

By providing structure and direction, the vocational rehabilitation program(s) were seen by the participants as one of the most positive parts of their experience and a significant contributor to their successes in returning to competitive employment. It was observed that it was too easy to stay at home and spend time watching television, staring out the window or generally doing nothing productive. Moreover, many said it was difficult to break this pattern. Having someone assist in providing structure and desirable goals made a difficult task a little easier. Through the provision of structure and direction, individual levels of motivation increased.

> (The program) made me motivate myself-- go out and go find job leads and stuff like that and they helped me go out to the jobs as well, to go apply for them. That's probably the push I needed. Really positive.

Theme 2 - Identification of Personal Strengths and Limitations. All of the interviewees stated that through their participation in vocational rehabilitation programs they were able to discover personal strengths and/or limitations.

> It was kind of beneficial to see how I could handle a routine and a job with specific tasks to do, trying to live up to some standard to the job. It's interesting. It just helped me, it probably helped me to determine what things I needed to work on.
>
> It (the vocational program) more or less showed me that we all have some kind of handicap and we all will find ways to work around the disability and to always strive forward to make yourself better, to learn.
>
> I believe that most, well, some of us have handicaps and the idea is just to get these individuals into a job that is going to be suited for his needs and ... not to become frustrated upon the, your abilities being somewhat slower than the regular person, but to think that you could help in some other aspects that can be enhanced - to discover your own strengths, we all have limitations.

Participation in the vocational rehabilitation program(s) was seen as a learning experience through the discovery of personal strengths and limitations--many of which had altered from pre-injury. Through this process, all 8 worked on maximizing their strengths and exploring ways to compensate for, or minimize the need for, their limitations.

Theme 3 - Increased Self-Confidence. Post-injury, low self-confidence prevented the majority of the interviewees from applying for jobs or performing to their maximum potential while on the job. Increased personal self-confidence was viewed by 7 of the interviewees as a major benefit of the vocational rehabilitation program(s) they had attended.

> It was confidence building for me, that was the big one.
>
> I feel pretty good now, it's getting better and better, especially after that practicum at (volunteer work experience), helped a lot.
>
> I can say that after working here, hands-on, I think I can cope, I'm sure.
>
> It's all small steps and then maybe I will make a big step. I am learning all the small steps now.
>
> It (work experience in hospital) gave me time to gain my self-confidence.
>
> The one I liked the most was the one at the (work experience in hospital) ... It wasn't the greatest job in the world, but it was mine and I was part of their little group and I was contributing again and, after a while, I thought, I knew, I could do it again ... doing something I could handle - something I succeeded in.

Socialization and Support. One theme emerged under this cluster:

Theme 4 - Socialization/Support. In addition to interpersonal factors, 6 of 8 individuals believed that the opportunity for social interaction and support they received throughout the BID Works vocational rehabilitation program was beneficial.

> The support (was most positive), support by my family and (the people in the program) too, to let me know that somebody cared, I don't know how to explain that, but that is a very important one.
>
> (T)he support has been helpful although I do some things myself now. The support has been good, the difference between forward and backward - a fine line.
>
> I think that's the biggest thing, people need to belong--to say all of a sudden I have this, I feel in unison with all the brain patients in the world, you know what I mean, because we're all a group, a classification. But everybody needs to belong somewhere, you need to feel you belong, therefore that's an important part of the

> group. When I was in the support group part I felt like I belonged somewhere even though I don't necessarily want to be classified as a brain patient.

Support is received in a variety of ways from a variety of people. Family members, peers in the vocational program(s) and program staff were cited most often as being the support for persons reentering the work force. Furthermore, support was received through social involvement and acceptance from co-workers on the job.

> The fellow workers I work with all day can be an inspiration to me. Now I am very eager to go to work day after day, because I can associate with these people I work with.
>
> It was good having somebody (a co-worker) there who I got to know reasonably well, at least who I felt confident enough to just look over and ask questions--somebody to help me if I needed

Minor Themes. Minor themes that emerged included individuation of program(s) and long-term follow-along. Programs that offer flexibility in design were perceived as having more chance for success by the interviewees. Long-term follow-along and the opportunity to return to the rehabilitation program for further assistance or aid if necessary at a later date was also cited as a positive factor.

Negative Aspects of the Vocational Rehabilitation Experience

The next question asked participants to identify the negative or unhelpful parts of their vocational rehabilitation experience. Table 6 outlines the cluster title, major and minor themes and frequencies.

Table 6

Negative Aspects of Vocational Rehabilitation

	Cluster Title	Theme Titles	# of Responses
Major theme			
	Timing		
		Lack of Motivation	6
		Perception of Work Readiness	6
Minor themes			
		Repetition in Vocational Education	3
		Frustration in Work Experiences	3
		Time Between Program Components	3

Timing. Vocational rehabilitation programs have had difficulty in determining when a person is ready to reenter the work force. The data in this study revealed two themes in relation to this cluster of timing: lack of motivation and inaccurate perceptions of work readiness.

Theme 1 - Lack of Motivation. Six participants stated that, at the beginning of their rehabilitation, they had a lack of motivation to fully participate in the program.

> (A Vocational program) never really had someone there to give you a push to employment, to give you an initiative to work.
>
> I say don't try and find work for me right now, ... but have an eye always open because you know my goal, and if you have something, then tell me, explain to me what you have, then maybe I will take it or I will say later on I will try something else. I don't know if that is fair or not.
>
> Every program has a few clients that have totally given up on life pretty well, they figure its all over after brain injury and it doesn't build any confidence or motivation in any one else having them whine all the time.

These respondents did not indicate that this lack of motivation was the responsibility of the vocational programs. However, a lack of motivation could be an issue addressed by the program.

Theme 2 - Perception of Work Readiness. Six of the 8 interviewees stated that, early in their recovery process, they thought that they were ready for the challenges of competitive employment.

> I wanted to go back to work right away, (after getting out of the hospital) but there is no way they would allow me.. I'm glad I didn't go back any sooner to be honest because I wouldn't have been able to cope, cause that was one of the hardest things is going back to work... That's when I took this program.
>
> When I came out of the hospital it was like I had cut my hand, I thought there would be no long-term effects, I was going to heal. Why would I need rehabilitation?
>
> At the time I thought I didn't need any help, I didn't think there was anything wrong with me and I tried to escape.

In retrospect, these participants understood that this perception of readiness was premature. This calls to question the issue of timing and the challenge of vocational rehabilitation staff being able to determine when a client is ready to participate in a program where the final goal is competitive employment.

Minor Themes. With respect to negative factors in rehabilitation, analysis yielded three minor themes including repetition in vocational education, frustration in work experiences, and time between program components. Each theme was reported by three individuals. With respect to vocational education, it was stated that resume writing and certain parts of job search skill were duplicated in the programs. These comments were made by those interviewees who had participated in more than one vocational rehabilitation program.

Frustration in the work experience placements was felt by three participants in their struggle to return to employment. This quote best exemplifies this theme:

> The one major thing is trying things, going to these different jobs and not being able to do them. Frustrating, very, very frustrating, because it was something that I tried that was jobs that I could have been able to handle in the past before the brain injury, and that I could do with no problem at all and then it would be jobs that I wouldn't have even looked at before, when I was a manager,I wouldn't have even thought of doing before.

Lastly, the time between the in-hospital volunteer work assessment and the community work trial caused some participants to criticize the process. It was suggested that the transitions could be smoother with less of a time interval between these stages.

Suggested Additions and Improvements

The final two questions dealt with the topic of how to improve upon vocational rehabilitation programs and return to work efforts. Question 7 asked individuals to suggest changes that would improve their vocational rehabilitation experiences. Question 8 solicited additional suggestions for program improvement. The first broad cluster of responses related to personal issues and the second related to the work environment. Table 7 outlines the themes and frequencies within each cluster.

Table 7
Suggested Additions/Improvements

	Cluster Title	Theme Titles	# of Responses
Major themes			
	Personal Issues		
		Personal Support	8
		Self Discovery	7
		Inclusion of Personal Interests	6
		Personal Control	5
		Vocational Education & Counselling	4
	Work Environment		
		Supportive Work Environment	7
		Work Experience	6
		Supported Employment	6
		Individuation of Program	6
		Ultimate Goal--Get a Job	5
Minor themes			
		Steps to Success	3
		Personal Responsibility	3
		Social Support	3
		Public Education	3

Personal Issues. This first cluster comprises major themes of personal support, self discovery, inclusion of personal interests, personal control and vocational education and counselling.

Theme 1 - Personal Support. All 8 of the interviewees expressed a need for varied types of personal support during their involvement in the vocational rehabilitation program. The areas identified for personal support included assistance in developing and maintaining motivation to work toward competitive employment, increasing self-confidence, dealing with frustration and understanding the effects of the injury.

> Even though they are too proud, or whatever, to say so the support should be definitely there.
>
> Look around and also go to groups...I think BID Works could help them. The quality of life would improve with BID Works support.
>
> The more I get support, the more I relax and become confident, the faster I think.
>
> There were times that I knew I could not fail because people were there and that nothing could go wrong when people were there.

Much of this support is provided by the vocational rehabilitation staff who work one-to-one with the client. Through honesty, a belief in the individual, and trust, each participant felt personally supported. A point that was made by one of the respondents is that this support must be withdrawn slowly and replaced by more permanent means within one's life (i.e., by family, co-workers) for job maintenance.

Theme 2 - Self Discovery. Seven of the interviewees talked about the need for vocational rehabilitation programs to give clients an opportunity for self discovery, to learn about themselves and about strengths and limitations.

> By going through some of these programs I know what to expect, so if somebody, for example, found a job for you at the corner drug store and that includes shipping and receiving, that is something I know I can do, it's something I can remember, I can do, then put it out of my mind, put it on the truck if that's were to put it, do it quickly and finish it.
>
> You have to know where you're limits are, my balance isn't the same, I can't carry as much as I used to, find out your limitations. ... I never knew where mine were, all I know is that my limits are less than they used to be.
>
> I guess sort of like structured meetings can be beneficial for the patient to help discover his weakness and his strengths and allow him to ... experience.

One of the beneficial factors of vocational rehabilitation, as stated by the participants in question 5, is the identification of personal strengths and limitations. This theme of self discovery is again emphasized by the interviewees as a suggestion for program inclusion. It is important that vocational programs determine how these personal factors of strengths and limitations transfer or generalize to competitive employment within the community and allow for personal experience and discovery. This discovery, at first, should ideally be made on an individual basis, and not derived on the basis of comparing one participant to another. It is important to establish what each of the respondents personally have to offer. This process should include feedback from rehabilitation staff and employers (wherever possible) to aid in the discovery process.

Theme 3 - Inclusion of Personal Interests. Six respondents strongly emphasized the need for programs to allow for personal interests in the selection of job placements. Some of the comments included:

> If you are a chef, you don't want to be a waiter. People have to want to go back to work, and know they are valued and have much to give. If they were at a higher level, then rather than drop them three or four levels down, let them just rather do part of their job or something that is the same, or maybe the same as what they used to do.
>
> I do not want to get work which I do not like. I do not know what I like at the moment. I do not know what I am able to do, you know what I mean. I don't know. I would like to be able to get work which I like. Don't get me wrong or something that I, that I will not work or that I want work that is easy for me or that I want to be able to go around and get money for free. No I want to get a job that I like and that which, I don't know, that I can live with normally ... There is no point in me going in and trying something that I don't like.
>
> ... but putting me in a place where I didn't want to be and going more just to try it, I don't want to be in this ... store, I've never worked that before, that's not something I want to do, I don't want to be in front of the public.
>
> Like you don't want them to do trigonometry or something ... just something that is related to whatever they want to do, nothing that's going to be too hard, nothing that is beyond their capabilities. Like you don't ask them how to do brain surgery or something, you know what I mean? But still be something that they are relatively knowledgeable about. ... You have to have an interest in it to make it work out.

To make a job placement succeed, the individual must have an interest and desire in the job to be performed.

Theme 4 - Personal Control. Five respondents asked for personal control over their vocational rehabilitation experience to varying degrees. Quotes included:

> (The program) probably could have given me more say in the locations or if I would have done some of the traveling with (staff), so the employers get a chance to meet me right away.
>
> The one thing that I, and I don't know if it would help other people get back to work or not, is, instead of being almost told that they found this job for you, you be much more involved.

Respondents want to be a part of the planning process. Planning must be conducted in conjunction with the participants along each step of the program. It is important that the participants feel a part of the process, and encouraged to see that they can be in control of their future and thus their lives.

Theme 5 - Vocational Education and Counselling. Vocational education and counselling were viewed by half of the respondents as vital components of the rehabilitation process.

> Personally, I believe that it is very useful that people (program staff) are willing to take the time, sit down and talk to the patient.
>
> Well, number one find out what his or her interests are, and if he/she doesn't already have a resume, help him/her make one. The mock interview for sure, because maybe some people haven't had much experience at that.
>
> Probably the main thing is, it would help motivate them, someone to help them to motivate themselves and how to market yourself to employers.
>
> It was easier and simple to go back. I had counselling and that made it easier.

Work Environment. Another broad cluster to emerge in response to suggested additions and improvements to vocational rehabilitation programs related to improvements that could be made to specific aspects of the work environment. These included supportive work environment, work experience, supported employment, program individuation and the ultimate goal of obtaining a job.

Theme 6 - Supportive Work Environment. Seven of the respondents talked about the support they need within a job. This support refers to employers and co-workers in the work environment.

> I can go on and try something with the people running the company or the group or whatever, they would very much have to be aware of my problem, or at least one of them would so they would be able to help me or point me in the right direction or tell me I was doing it wrong or anything like that.
>
> The (employer) knows that if I do something wrong that I am not jerking around or playing or anything else. That he realizes that I am trying to do it right. Understanding of the injury and awareness are better words.
>
> Well, pretty much set in my ways and perhaps I don't come across totally proper sometimes, so employers thought I wouldn't be interested in learning anything new, so its important for employers to understand (the brain injury).
>
> I would like to go back to work and I'm not sure I can, I cannot start a job without people around not knowing that I have this memory loss, it's that simple, because like I said, I look normal.

These seven respondents stated that they would be more likely to gain and maintain employment if their brain injury was understood. Interviewees perceived they would be given the opportunity to prove that they are able to perform the job and, with the understanding of employers and co-workers, would be able to establish needed on-the-job supports. Aiding in the establishment of this understanding of brain injury is a challenge for the service provider.

Theme 7 - Work Experience. Six people felt that the in-hospital and community work experiences were beneficial to the rehabilitation process. The importance of volunteering was clearly identified by the interviewees. The following comment was made:

> I think it would be beneficial to go and do a work experience, to feel productive again, for training, get used to working again, at first they feel lost and frustrated on the first couple of days at work (- get back into it).

Interviewees stated that work experiences provided invaluable learning opportunities. They felt that the in-hospital and community work experiences helped them get back into the work force at a gradual rate, enabling an easier progression to competitive employment. This was seen as a positive experience recommended to others entering vocational rehabilitation. Again, it must be mentioned that individual needs must be considered in this work placement or experience process. For example, someone

who has been out of the work force for a number of years may require a more gradual reentry than someone who has had employment for longer periods post-injury.

Theme 8 - Supported Employment. Six interviewees suggested that supported employment remain part of the vocational rehabilitation process. By supported employment we mean job coaching--providing help and support while on the job. This can be implemented within a volunteer work experience and within competitive employment.

> ... making sure that I have at least one person around me that can point me, help, that's the support.
>
> You have to have someone watch or demonstrate things.

One of the interviewees who was not provided with supported employment once she progressed to competitive employment, felt this was a serious omission in her rehabilitation.

> (BID Works) needed to be there just a little bit longer to help me through it, ...the contact once you get back to work, that's got to be more intense. ... Even though they (participants) are too proud or whatever to say so, the support should be definitely there.

Respondents stated that timing must be considered. They felt that supported employment was not a permanent solution to the difficulties many persons with brain injury face. A job coach must work him or herself out of a job in the process of helping the participant to become as independent as possible on the job. If long-term aid is required, this should be supplied within the work environment. The interviewees emphasized that the job coach should not be within the work environment any longer than necessary. They identified a strong need to have maximum personal responsibility and independence.

> ... after that (training), not treating me like a baby, but allowing me to do it myself. In my experience this has sometimes happened and sometimes not.

Theme 9 - Individuation of Program. Individualizing the vocational rehabilitation process was already discussed in the responses to question 5. When asked what

considerations the vocational rehabilitation program must make in order to best serve the participants, this point was again raised by 6 of the 8 interviewees.

> Individualized. That kind of subtext of the program, makes you build confidence in the person that you're helping, makes him feel ok because he feels he did most of the work on his own, he got the job because he went out and applied for it.
>
> Well, the way it was explained to me, like the volunteer part, she said, you volunteer for a while, I didn't understand that because I was higher functioning than some people that are in the program so I didn't feel I needed to do a volunteer program.
>
> I'm sure the parts that weren't necessary were necessary for somebody else.
>
> It needs to be flexible enough to suit the individual - not just 'here are employers - go get a job'.

Personalizing and individualizing the program allows for individual differences. People are not all the same including those recovering from a brain injury. Of course, there are commonalities, but to fit clients into a rigid program will likely not maximize success. By viewing each person as a unique individual and designing programs that emphasize his or her strengths, more persons recovering from brain injury may reach and maintain the goal of competitive employment.

Theme 10 - Ultimate Goal--Get a Job. Five participants in this study stated that the ultimate goal for them within this rehabilitation program (BID Works) was to get and keep a job. They felt this should be the driving force behind the program, and indicated they would participate in most of what was asked of them if they feel that their goal might be realized.

> I believe that most, well, some of us have handicaps and the idea is just to get these individuals into a job that is going to be suited for their needs.
>
> Also getting back to work is very important to me, a job is something I must have.
>
> I don't know, but there's more. and it's hard but there are gains that I make and will make. It's a goal, such a major goal - to work. I could stay home and receive my cheque anyway. It's a quality of life, that's the thing.

Some of the interviewees felt that once they have a job, their rehabilitation is complete--they are "normal" again. Employment is viewed by many as being the ultimate goal, the final step. Research also emphasizes this by measuring rehabilitation success by whether the person has paid employment or not. Respondents believe that

once this is reached, they will be a part of society again and life will continue on the same track as pre-injury.

Minor Themes. Four minor themes were identified in these questions about additions and improvements to vocational rehabilitation programs. These included steps leading to success, personal responsibility, social support, and public education.

First, it was felt that a program should build small steps, that a participant will succeed in the rehabilitation process in order to increase self-confidence and self-esteem. This will, in turn, influence work performance and motivation. One interviewee commented:

> Get people to succeed in the little steps and then go on. ... The future is as bright as you want it to be. You'd be surprised how higher self-esteem can get 'the computer' (the brain) going. I know in the past it has been difficult and the world is a dark place, and the steps can take you higher, and for me one of the steps was going to BID Works. You know you don't have much or any self-esteem, self-confidence any more, but the small steps, and if you can get someone to succeed then he/she will be able to build self-confidence, and you know that next week will be better.

The next minor theme emphasized the need to recognize personal responsibility in the vocational rehabilitation process. If a person is not willing to work towards competitive employment, failure is imminent. "It is like a child with a musical instrument, and if he wants it to happen he will start to practice and practice and I also had to do that." In a further theme, 3 participants felt it was not enough to have family, staff and friends' support. Support from others who have also had brain injuries and who have experienced or are experiencing similar difficulties may be of great benefit in attempting a return to work. Some form of support group may fill this need.

The final minor theme to emerge related to the perceived need for education of potential employers, co-workers and the general public. It was felt that the general population had preconceived and often false notions of brain injury and this negatively

affects the individual recovering from brain injury when attempting to reenter the work force.

Conclusion

The respondents expressed barriers and aids in general attempts to return to work. As well, positive and negative aspects about the vocational rehabilitation process were revealed. Overall, they felt that the vocational rehabilitation program(s) were well worth the effort, both for those who were successful at the time of the interviews and those who had not yet atttained their final goal.

The interviewees who volunteered to participate in this study were very open and shared freely their successes and failures. In many cases, the research participants demonstrated great tenacity and courage in their struggles to return to work. The 8 participants showed much perseverance and determination. Their tenacity was typified by high levels of personal desire and motivation to return to work.

Chapter 5

Summary, Implications and Recommendations

This chapter starts with a brief summary of the research study outlining the research questions and data collection procedure. The major research findings are briefly summarized and implications for vocational rehabilitation programs discussed. The chapter ends with recommendations, further research suggestions, and concluding remarks.

Summary of the Study

Even with tremendous advances in medicine and technology, it is not possible to repair damage that occurs as a consequence of head trauma. Medical science has reduced the amount of damage that may occur at the time of the trauma and shortly after, thereby saving many lives that would have otherwise been lost. These lives, however, are changed forever by the effects of brain damage.

One of the most drastic changes for many of these people is with respect to work. Evidence is incontrovertible that persons with brain injury have poor return to work rates (Brooks et al.,1987; McMordie et al., 1990; Oddy et al., 1985; Wehman & Goodall, 1990). Often these individuals are required to engage in specialized vocational services to reenter the work force because of the effects of the brain injury. This study focused on the job reentry experiences of adults (age 16 and over) who had experienced a moderate to severe brain injury. Specifically, this study explored factors that respondents themselves perceived as being of primary importance in a vocational rehabilitation program. The research questions addressed in this study were:

What factors affect return to employment from the perspective of individuals who have sustained a brain injury?

What can be done to facilitate and improve the rehabilitation process from the perspective of individuals who have sustained a brain injury?

This study utilized qualitative research methods to understand the individuals' experiences as they articulated them. A semi-structured interview format was utilized for data collection allowing 8 participants to provide a unique in-depth view of their experiences. All interviews were transcribed verbatim. Responses were analyzed and categorized into major and minor themes within each of the questions asked. Further, major themes were grouped into subordinate clusters for simplicity and clarity of presentation.

Findings

This study identified a range of factors that were relevant to vocational rehabilitation and return to work. Common experiences were reported by all respondents to varying degrees. Positive factors, or identified major themes in attempting to return to work, included support from family members, others in the rehabilitation program, rehabilitation staff and co-workers. The participants interviewed wanted people around them who believed in them, helped them gain an increased belief in themselves and assisted them in re-establishing a work role within their community.

In general, participants believed programs did, to varying degrees, assist them in their endeavors to return to work. However, they firmly believed that a program designed specifically for this population would serve them best, and continually emphasized the need to be treated as individuals. Their commitment to the rehabilitation process was also admirable. They even indicated that, despite not seeing the importance of certain components in a vocational rehabilitation program, they would participate in almost anything for the ultimate goal of returning to work. However, they emphasized the fact that they wanted to be active participants in their rehabilitation process.

It was also apparent that there are, and will likely always be, barriers to returning to work for persons who have sustained a brain injury. Most often quoted were the effects of the brain injury and the personal acceptance of these effects. Many have a reduced level

of self-confidence and self-esteem, and a definite sense of change in the self, underscored by the belief in a departure from "normalcy." The effects of the brain injury for these interviewees resulted in significant changes in emotional, cognitive and social functioning which, in turn, affected their return to work. In addition, lack of experience in new occupational areas and attempting to enter the work force too early in the recovery process were perceived as hindrances.

Beyond the adjustments that were needed within the person, barriers in the environment were also recognized as significant factors in return to work. These factors include the present depressed economy and lack of employer knowledge about brain injury. These barriers tended to challenge the already strained resources of those with brain injuries. Persons experiencing cognitive and/or physical challenges are often overlooked or not considered for positions, regardless of their ability. Employers may be reluctant to "take a chance" on a person faced with perceived limitations.

In spite of these barriers, there are many positive factors that were experienced by the participants in attempting to return to work. Factors including support from family, peers, co-workers and rehabilitation staff, readjustment of vocational goals, motivation to return to work, and involvement in formal rehabilitation seemed crucial to the attempts people made to adapt. These are aspects that must be continually enhanced and nurtured.

Once involved in vocational rehabilitation program(s), interviewees felt more productive and purposeful, and perceived increased self-confidence and self-esteem. The program(s) helped them to identify strengths and limitations to varying degrees and the structure provided opportunities for social interaction and, with this, much needed and appreciated support from others.

Some negative factors within vocational rehabilitation programs were identified. First, it was felt that programs needed to motivate individuals to fully participate in the vocational rehabilitation process. Motivation of individuals with brain injury may be an

enduring difficulty within this population that needs to be addressed. Second, very early in the recovery process, many people believe they are ready for the challenges of competitive employment. When persons attempt to return to work too early in the recovery process it often leads to very painful disappointment and even failure in their attempt to maintain their job. This is an issue that relates to insight and awareness which is clearly documented in the literature (Prigatano, 1992). However, further research is required to more fully understand timing--when in the recovery process an individual is ready to return to competitive employment. Second, future studies may find ways to overcome or minimize this apparent lack of insight or awareness.

Program Implications

To be worthwhile, a research study must have value beyond the mere completion of the task. It should add to the body of existing knowledge, outline potential new approaches, suggest changes, or point toward new directions for research. This thesis may provide information to help vocational rehabilitation program personnel improve their knowledge and services to persons who have sustained a brain injury.

Suggested Additions and Improvements. All participants were asked for suggestions for additions and improvements in vocational rehabilitation programs. In this section, these identified themes are underlined, discussed, and suggestions made for implementation within vocational rehabilitation programs .

The ultimate goal of most that enter into vocational rehabilitation programs is to reenter the work force. This is not surprising when it is considered that people identify others through their occupation. People, in turn, establish their own identity on this basis. More often than not, after a brain injury, a person cannot work for an extended period of time, losing this identification. Clients struggle to regain this role in their lives. One respondent stated, "Even if you win a lottery, you reach a point you have to return to

work--assimilation back into society." A vocational rehabilitation program should always keep this in mind and aid the client to work toward his/her ultimate goal.

Participants want the programs to be designed for the individual. As the literature indicates, effects of brain injury are varied among individuals. It is important that programs reflect this individuality. Intense follow-along and the opportunity for program reentry are two ways to allow for individuality in program design. Programs should provide comprehensive follow-along, such as regular phone contact with the client and the employer, to be able to intervene early in instances of work difficulties or crisis. As well, the program should allow reentry into those components that a client may require, such as community work experience or vocational education.

The participants should be encouraged to assume personal control for the establishment of their own vocational goals. Emphasis should be placed on the establishment of mutual goals at the beginning of the client's entry into the program. It is advocated that there remain input from the rehabilitation staff in this goal establishment. This staff member can aid the client with awareness and insight into difficulties many participants experience in their recovery from brain injury, thereby helping to establish appropriate and attainable goals. If possible, goals should be formally made in writing and every effort made to ensure all parties are clear about the individual's program plan, structure, and time constraints toward his or her goal. This plan ought to be continually evaluated and revised to meet the needs of the client. This contract should also contain the clear understanding of the responsibilities of all involved. The program cannot succeed in those things that a participant does not want to attain. Within this individual plan, the client must be aware of his/her personal responsibility, what is asked of him or her in the process. As well, service providers should make the participant aware of how staff can help the participant in the process. Both can then work together towards the established goal with clear understanding of responsibilities.

It must be considered that competitive employment may not be possible for all persons recovering from brain injury that enter a vocational rehabilitation program. Ideally, a program should not only provide services for competitive employment, but should also provide final employment outcomes at varying stages of the process. The final goal may be a volunteer job within a safe and accepting environment (such as a hospital), a community volunteer job, a subsidized job, or a part-time competitive placement. If the vocational rehabilitation program cannot provide the individually needed services, links need to be established with other programs in the community which can meet these needs, such as community integration programs or volunteer centers. More harm than good can be done if a person is incorrectly allowed into a program. As one participant stated,

> Don't set people up for failure, figure out some way to see if they have the potential to succeed in competitive employment. In the short-term it may seem cruel to say to someone that competitive employment should not be a short-term goal at this time, but in the long run it is the right thing to do, reduce frustration and failure; we already have enough difficulty with self-esteem.

It was recommended by the participants in this study that work experience remain a key component to any vocational rehabilitation program. Benefits expressed from having participated in a volunteer work placement included increased self-confidence and an opportunity for self discovery. Respondents stated that, in looking back on the program, the work experience was a key component to successful work reentry. The starting point, be it a safe volunteer placement or one that more closely resembles community competitive employment, must be chosen in accordance with participant's needs and level of work readiness.

Throughout the interviews, respondents stated that the BID Works rehabilitation program was a learning process, an opportunity for discovery of personal and vocational strengths and limitations. First, in personal discovery they learn about themselves, not in comparison to others, but what they personally are good at and could offer. This helps

participants start answering the commonly asked questions of, "Who am I?" and "What can I do?" (Willer, 1994). Second, if the goal for the individual is competitive employment, discovery must go beyond the personal to discovery of vocational strengths and limitations. It may be more appropriate to provide this discovery within a safe environment that allows for and encourages experimentation and then the participant can progress to a new environment in the community. If the final goal is competitive employment, the skills must be compared to those needed in the types of jobs the individual is interested in filling in the community. Honest and direct feedback from vocational rehabilitation staff and work experience supervisors/employers is essential to the process toward competitive employment. When the individual is applying for a job, an employer will require him/her to be productive and an asset to the organization. Clients discover their limitations and learn to understand the need for compensation of these limitations and how to use learned techniques spontaneously or automatically. The ideal is to find work where the need for strengths are maximized and limitations are minimized with the use of compensation techniques.

Beyond an understanding of an individual's strengths and limitations, the respondents strongly believed that personal interest was one of the major components in work placement and maintenance. A job must meet not only financial, but also personal needs. Without a legitimate interest in following through with the placement, the experience will fail.

Supported employment, or job coaching, was identified as a positive feature by most respondents. This assistance not only helps actual learning and performance of tasks on the job, but also provides positive feedback, motivation and emotional support. Vocational rehabilitation staff have the opportunity to provide a step-by-step process (i.e., a placement in-hospital with minimal expectations and pressures progressing to a community placement closely reflecting a competitive job) so the individuals can

experience success. The interviewees believed that, through this process, they gained motivation, drive and self-confidence required to meet their ultimate goal. Rehabilitation staff must work towards withdrawing work and emotional supports slowly and replacing those with participants' new found confidence, independence and alternative sources of support. Within the participant's work environment, this support can be provided by co-workers, supervisors and employers if educated about the needs of the person recovering from brain injury. If workers are helped to understand effects of a brain injury and are felt to be of use, they are generally better equipped and willing to help their co-worker.

The client's family can best provide permanent stability, as well as emotional and social support. This means that these key people should be involved in the vocational planning process and helped to understand how they can provide personal support to the individual to aid in the process of job attainment and then job maintenance.

Further, persons involved in vocational rehabilitation programs need social supports. Social isolation is the reality for many people who have sustained a brain injury. People get much of their daily socialization from their work setting. A job coach has a unique opportunity to assist in forming social links within the client's work environment. All programs provide for adaptation and modification of the physical environment, but the human or social environment is often ignored. It is suggested by this study that through education and support for co-workers, a job coach can help those in the work place to be more knowledgeable, accepting and supportive.

As well, other participants in the program can provide social supports. These individuals have similar experiences, successes and difficulties. A support group provides an opportunity to learn from each other and supplies much needed psychosocial supports.

Vocational education and counselling primarily offer participants an opportunity to discover their work interests in-depth and teach skills to attain and maintain a job. Key for

implementing vocational education is to ensure that what is being taught has relevance to the participant--it must have practical value and be put into practice by the client.

Participants also identified a need for public education. Public education can be viewed in three domains: First, educating the general public for the goal of disputing myths; second, educating potential employers about the possibility of job attainment and, third, educating employers and co-workers for increased understanding to aid in job maintenance. Through public education an overall increase in understanding the effects of brain injury will ultimately open more doors for persons with brain injury. Unless employers are willing to hire persons with a head injury, vocational rehabilitation efforts may prove fruitless.

Further Implications. It must be noted, however, that this study does not suggest that vocational rehabilitation programs should be based solely on clients' perceived needs and wants. It would be counter-productive to ignore all of the well-researched and proven effective components that are a part of many vocational rehabilitation programs. However, it is anticipated that by having in-depth information of the respondents' perceptions of their experiences and by implementing their suggestions for improvement it may be possible to increase success rates for returning to work for this population.

The information provided in this study may be of use to a number of individuals directly and indirectly involved in vocational rehabilitation of persons with brain injury. This includes policy makers, programmers, evaluators, trainers, service providers, and persons recovering from brain injury, their family and supports.

First, policy makers can use the results to provide program direction to best serve this population. By having a better understanding of the perceived needs and wants of the clients one is serving, programs can be directed towards better serving this population.

Second, programmers who design the rehabilitation process may benefit from the study results. The people participating in these programs are adults and, therefore, will display the characteristics of adult learners, but beyond this, with increased distractability, learning disabilities and difficulty with memory, many of these characteristics are intensified. For example, the curriculum development process for educational components of rehabilitation may use this knowledge to provide relevant and practical exercises. It was emphasized that information is only usable by this population if it has immediate applicability to their lives.

Third, those persons involved in evaluation of vocational rehabilitation programs now have the opportunity to design better questionnaires for surveying the population served. This will not aid directly in collecting outcome data (i.e., number of people placed in competitive jobs, retention rate), but focuses more on the perception of the clients--how do they feel the program is aiding them towards competitive employment. It is believed that the better the clients perceive the process, the more likely success will follow.

Fourth, service providers are the front-line workers--those that have the most direct contact with persons recovering from brain injury. It is anticipated that allowing a glimpse into the lives and the perceptions of the participants will increase the sensitivity of those working with this population. The study serves as a reminder to listen to the voices of the people they serve, and to attempt to understand their needs and wants.

Also, persons providing the education for service providers would be advised to include sensitivity training. Effective service providers have a good understanding of the needs and wants of the population they serve and can work with them to achieve established goals.

Sixth, persons recovering from a brain injury, their family and other supports in their lives may benefit from the results. It may provide understanding of feelings, legitimization of feelings, suggestions for goal establishment and motivation and hope for

goal attainment. Family members and supports may have a better understanding of the importance of providing support and how to aid the individual in goal attainment.

The final implication of this study is that it contributes to the current literature and knowledge relating to vocational rehabilitation for persons with brain injury. Most of the current literature is based on American research, and this study is valuable in that it provides a Canadian perspective.

Overall, the research study was intended to provide data which could be used to improve or refine existing practices. The goal is to reintegrate those recovering from brain injury into the community and assist them towards maximum self-individuation and actualization.

Recommendations

A number of recommendations arise from the analyses conducted in this study. First, it is known that the brain injury population's life expectancy is average: many brain injuries occur at a young age, meaning that individuals with brain injuries have many years of potential work opportunities remaining after sustaining their injury. Vocational rehabilitation remains fundamentally important to these individuals. Comprehensive vocational rehabilitation programs must be made available for those that require assistance.

Second, there is a need for the modification of tax codes and budgetary appropriations to support the cost of serving the needs of those with head injuries (DeJong et al., 1990). Public policy needs to foster the growth of the community sector in providing for the needs of people with head injuries (DeJong et al., 1990). The federal government must be commended for funding programs such as BID Works in the Edmonton area. Unfortunately, there are still many rural and urban areas that do not have access to money or resources for vocational rehabilitation. Precious rehabilitation time

may be lost because of lack of funding and programs. These programs have generally been demonstrated not only to benefit the individuals concerned, but also cost-benefit analyses suggest rehabilitation produces optimal outcomes, savings in health care resource consumption and related societal costs (Abrams et al., 1993; Cope & O'Lear, 1993). It is recommended that access to vocational programs be made more widely available and fully accessible to all persons with brain injuries.

Third, participants in this study identified economic barriers to reemployment. It is recommended that incentives be offered to employers to hire persons recovering from brain injury. The final step for a vocational rehabilitation program is for the person recovering from brain injury to be reemployed. Finding potential placements, at present, is very difficult. In light of the benefits to society of rehabilitation and return to work (Abrams et al., 1993), employers should be given incentives to offer positions to varied populations including individuals recovering from brain injury. This may be accomplished through a combination of legislation, policy changes, education, economic incentives and even supported employment. In addition, provision of specific education about brain injury to employers and colleagues of individuals who have experienced a brain injury may foster greater acceptance and understanding of those with brain injuries in the work environment. Concomitantly, this education service provides a valuable secondary function in contributing to public education about brain injury in general. Obviously such educational programs have to be conducted in a sensitive manner that does not stigmatize or disadvantage individuals with brain injuries.

Fourth, it is recommended that institutions training future rehabilitation workers focus a part of their program on teaching about brain injury and rehabilitation in this area. Most educational programs at present do not address this population and practitioners may, for example, resort to outmoded rehabilitation approaches, treating brain injury like developmental disability. This approach has not been successful.

Fifth, many participants emphasized the importance of returning to work, at times conceptualized as a sign of return to "normalcy." For many with brain injuries, return to former vocational status is not feasible, the knowledge of which leads to significant frustration, even despair. Rehabilitation programs may need to help the individual focus on developing new and different roles within society and work towards understanding the new "self" and "sense of identity" that has emerged as a consequence of the injury. Returning to work is only one societal role. Other roles must also be encouraged, such as volunteer activities, sports and recreational activities and family member (ie., father, wife). In part, this issue relates to a need to re-examine criteria by which successes are measured or defined with respect to rehabilitation program outcomes.

It is understood, however, that the suggestions made in the implications section need to be placed within a realistic framework. Funding is not limitless in this age of fiscal restraint. It would be unrealistic and undesirable to suggest total individualization of rehabilitation. Cost effective and cost efficient implementation of rehabilitation remains a high priority. However, cost-benefit analysis strongly suggests that rehabilitation of those with brain injury is in the long-term an enormous benefit to society, not only from a psychosocial perspective, but also from an economic perspective (Barry & Schafer, 1993; Cope & O'Lear, 1993). Further, research shows that vocational rehabilitation for brain injury is also economically viable (Abrams et al., 1993).

Suggestions for Further Research

Future research could benefit from utilizing larger samples. Moreover, this study relied largely on a heterogeneous population of participants with brain injuries. For example, differences in the cause of injuries and differences in premorbid functioning levels may be factors that need to be incorporated into future studies. Further research aimed at validating, empirically, the themes derived in the present study, either through additional qualitative research or quantitative studies is required.

A further area needing more research is the determination of readiness for competitive employment. The respondents in this study all stated that they thought they were ready to return to competitive employment early in their recovery process. In retrospect, this feeling of readiness may have been premature. Self-report of work readiness may therefore not be an accurate measure. At this point, vocational rehabilitation staff need to understand more about the determination of work readiness and the ways to accurately identify and predict who is ready to participate in vocational rehabilitation programs. Exploring the relationships between the length of time after injury, involvement in rehabilitation programs, and return to work outcomes may be illuminating.

Another suggestion for further research is to determine the most efficient and effective employer incentives to hire persons recovering from brain injury. Without a chance at employment, vocational rehabilitation remains a fruitless endeavor. In the area of alternative legislation, Canada may choose to investigate the viability of implementing legislation as in the British model, requiring employers to hire a certain percentage of persons with disability (Krefting, 1987).

Conclusion

This study explored factors and experiences articulated by individuals with brain injuries with respect to their attempts to return to competitive employment. A valuable feature of this study is that it focused on the perspectives of the person with the brain injury. This study allowed persons with the injury to voice their opinions about their rehabilitation experiences and to identify factors of importance that assist people with brain injuries to return to competitive employment. Present vocational rehabilitation studies for brain injury show current rehabilitation programs do result in at least some improvement in return to work statistics when compared to no intervention (Abrams et al., 1993; Bistany, 1987; Goll & Hawley, 1989). Clearly, however, present research

indicates that there is room for improvement of existing programs, in what can be described a relatively new and evolving field.

Without optimal rehabilitation, the potential loss of earnings, the expenses to society, and the negative impacts on quality of life for persons recovering from brain injury and their family are immense (Kreutzer et al., 1988). This study has offered a glimpse into the lives and the perceptions of eight participants recovering from brain injury. It is hoped that the insights derived from this study may improve vocational rehabilitation for persons recovering from brain injury and contribute to improved quality of life for these individuals and their families.

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Appendix A

Interview Guide

Interview Guide

Demographic Information

Age _____

Gender_____

Education _____

Marital Status_____

Brain Injury Date_____

Cause of Brain Injury _____

Length of Coma _____

Length of (Post-traumatic) Amnesia_____

Current Living Arrangement_____

Work Prior to Brain Injury_____
_____
_____
_____

Length of Unemployment_____

Start of Job post-Brain Injury (if relevant...)_____

End date (if relevant...) _____

Reason for termination (if relevant)_____
_____
_____

Questions:

1) Tell me about your experience in trying to return to work after you sustained a brain injury._____

2) What factors hindered you in your attempt to return to work?

3) What factors helped you in your attempt to return to work?

4) Are there any other factors which may have influenced or affected your attempts to return to work?

5) Can you tell me about the positive/good/beneficial factors of your vocational rehabilitation experience?_____

6) Can you tell me about the negative/bad/not helpful parts of your vocational rehabilitation experience?_____

7) What would you change to improve your vocational rehabilitation experience?

8) Do you have any other suggestions on what more could have been done to help you return to work?_____

9) Do you have any other comments or questions about the interview or the information presented?_____

Appendix B

Consent Form

Consent Form

Research Title: Work Reentry After Brain Injury

Researcher: Ellen Boelcke
Supervisor: Dr. P. Brook (Associate Professor)
University of Alberta
Faculty of Education
Department of Adult, Career and Technology

This is to certify that I agree to participate in the above study. Having been contacted by the researcher, a graduate student in the Department of Adult Career and Technology, I understand:

1. the purpose of this study as explained to me.
2. my name will not be disclosed at any time during this study or used in the resulting thesis.
3. any information I provide to the researcher will be kept confidential and used solely for the purposes of this research study.
4. I am participating in this study on a purely voluntary basis, therefore, I have the right to quit or refuse to participate at any time.
5. the results of the study will be made available to me if I so request.
6. I have been fully informed as to the nature of the study and my involvement in it.
7. the thesis this study will lead to will be available for examination at the University of Alberta Library.

Signature of Participant _____ Date _____
Signature of Guardian (if applicable) _____